California's

Ryan White Grantees' Statewide Coordinated Statement of Need

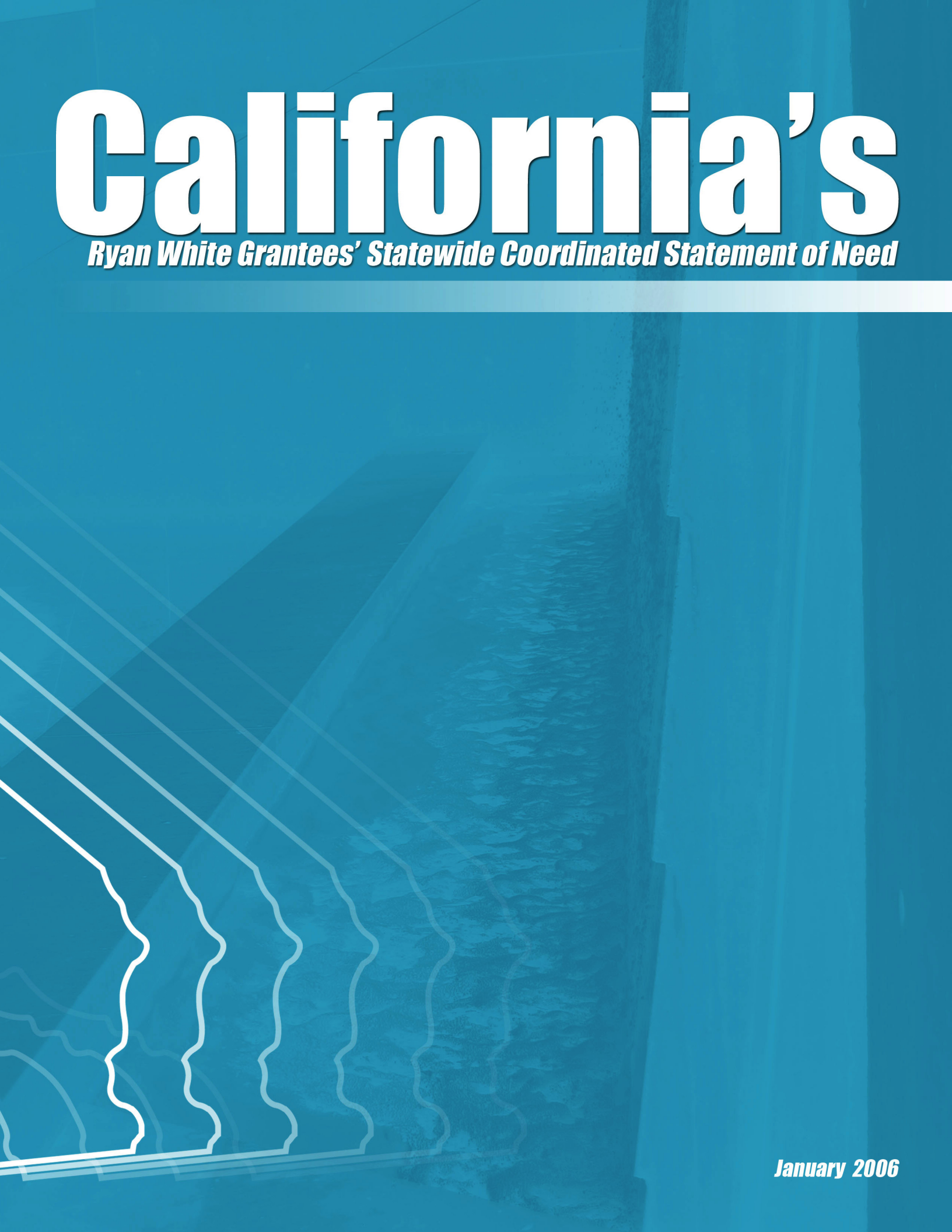

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Table of Contents

Introduction

This Statewide Coordinated Statement of Need (SCSN) was developed to document the needs of people living with HIV/AIDS (PLWH) in California and to comply with a funding requirement for Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds. The development of this document was coordinated by the California Department of Health Services, Office of AIDS (CDHS/OA), and was made possible through an extensive process of collecting input and documentation from the many CARE Act grantees throughout California, Title I Planning Councils, consumers and community advocates, and other state agencies. PLWH were a key part of the process. It is based on the many HIV/AIDS needs assessments conducted across the state, and was collectively funded by all California CARE Act grantees, as required by the CARE Act.

Legislative Requirement for SCSN

SCSN is required by the CARE Act. Section 2617(b)(5) of the federal legislation requires states to submit an application for funding that contains, in part, "an assurance that the public health agency administering the grant for the State will periodically convene a meeting of individuals with HIV disease, representatives of grantees under each part under this title, providers, and public agency representatives for the purpose of developing a statewide coordinated statement of need."

Each CARE Act grantee, including Title I, Title II, Title III, and Title IV, is required to document that their services are consistent with SCSN. For example, Section 2617(b)(4)(F) requires the Title II grantee to provide "a description of how the allocation and utilization of resources are consistent with the statewide coordinated statement of need (including traditionally underserved populations and subpopulations) developed in partnership with other grantees in the state that receive funding under this title."

Purpose of This Document

This document meets federal legislative criteria for receiving CARE Act funding in the state of California, and is submitted to the Health Resources and Services Administration (HRSA) to comply with that criteria. Moreover, this document is also intended to inform OA, health planners, local health jurisdictions, and community advocates about the needs of PLWH in California. Organizations applying for CARE Act funds can use this document to ensure that their programs will help meet the needs identified in this document. It will be used to educate policy makers and funders about the needs that have been met, the gaps and barriers that continue to exist, and the many services urgently needed today. As changes are being proposed to the CARE Act through reauthorization, it is hoped that this document can provide useful information to help inform the reauthorization process of the needs of PLWH and the challenges that they face.

Executive Summary

Process

The production of the SCSN was coordinated by the California Office of AIDS, the Title II grantee, OA. The process used to develop the California SCSN was comprehensive and inclusive. It incorporated existing needs assessments and consumer input from each of the California Eligible Metropolitan Areas (EMAs), needs assessments, and program descriptions from the Title III-, Title IV-, and Part F-funded agencies, input from the California HIV Planning Group (CHPG), a state-sponsored meeting to review a draft document and provide additional input, and extensive review by the Title II grantee. It is consistent with the most recent Title II Comprehensive Plan for California. PLWH were included in the process at every step.

Epidemiological Profile

California is a large and diverse state with a large and diverse HIV/AIDS epidemic. As of November 30, 2005, 139,094 AIDS diagnoses and 39,717 HIV infections had been reported in California. The epidemic in California is predominantly among gay/bisexual men and among Whites, although the proportions of cases that are women, heterosexual, and people of color continue to increase, and African Americans in particular are disproportionately represented. The number of individuals diagnosed and reported with AIDS, and not reported as deceased, has grown steadily across all demographic groups since 1990; people living with AIDS have increased by 263 percent since 1990. As of November 30, 2005, 57,961 adults were living with AIDS in California, and an additional 39,692 adults and adolescents were living with HIV. HIV reporting was implemented in 2002 in California, and the number of reported cases is still below the HIV prevalence estimated by OA.

Overarching Issues and Needs

SCSN identifies gaps and barriers to care. The following are the overarching issues that touch on multiple services, populations, and barriers to care.

- CARE Act services must be available, accessible, and culturally and linguistically appropriate across all populations and service categories.
- The existing system of HIV service or support needs to continue to adapt its way of doing business in order to effectively address the emerging needs and increasing complexity of care for expanding HIV-affected populations.
- The capacity for enhanced evaluation across the entire system of care must be expanded in all regions of California, including across all CARE Act titles and systems of care, and throughout the state as a whole.
- Increased resources could address nearly all of the service gaps and barriers to care described in this document.

- The number of Californians turning to CARE Act-funded services is higher than it has ever been, and the number of PLWH continues to grow.
- Reauthorization has the potential to exacerbate the current problems.

Overarching Goals

- Provide to all PLWH in California the services necessary to sustain and support their health and quality of life, regardless of income or ability to pay, and across all stages of illness, by maintaining and enhancing California's community-based system of HIV/AIDS care.
- Give all PLWH in California immediate access to high quality, culturally competent HIV primary medical care and treatment, including medications.
- Deliver HIV/AIDS services in California in an equitable, client-centered manner, that respond sensitively and appropriately to client age, gender, cultural group, language, sexual orientation, income, region or residence, family status, health status, incarceration status, and legal residency status.
- Ensure that HIV/AIDS services in California are delivered by experienced, competent, and fully trained providers who are knowledgeable about and responsive to their communities, and who understand and represent, to the extent possible, the cultural, linguistic, and community backgrounds of the clients they serve.
- Expand the participation of PLWH at all levels of HIV/AIDS planning, needs assessment, systems design, service implementation, and evaluation in California; and enhance opportunities and incentives for this participation.
- Maximize the number of PLWH who are aware of their status by supporting expanded targeted HIV testing efforts and linkages into care.
- Reduce new HIV transmissions by expanding effective prevention services for PLWH.
- Increase evaluation efforts and approaches that allow us to better assess the quality of care provided to PLWH, and to better document the outcomes and impacts of HIV care and services on the lives and health status of PLWH. To continue to evaluate the services and interventions and to use the evaluation data to improve and expand services to meet new and emerging needs as well as long-established needs. To use epidemiologic data and research findings to design and target services to those most in need.

Specific Care and Treatment Goals

This section lists the goals for each of the service, population, and issue categories in SCSN.

Access to Care

- Fund and support outreach services for PLWH. Train community health outreach workers in effective outreach methods.

- Conduct ongoing research to identify and determine the service needs of those not in care and the barriers that are keeping them out of care. Identify and address the root causes of why they are not in care.
- Design and support services to bring PLWH into care and produce better health outcomes. Expand targeted outreach programs to find those who have been lost to care as well as those newly diagnosed.
- Identify or develop additional funding streams to support expanded program capacity for those who are currently not in care.

Ambulatory/Outpatient Medical Care and Drug Therapies

- Continue to make the availability of comprehensive, high-quality, and culturally competent primary medical care the first priority within the spectrum of CARE Act-funded care within California. Ensure the universal availability and subsidy of all appropriate new and existing medications and drug treatment combinations for all eligible persons with HIV who are deemed medically appropriate and who wish to receive them. Support programs that help and empower clients to understand and adhere to complex medication regimens, in order to maximize the benefits these treatments can provide.
- Ensure continuing professional competence in prescribing and monitoring medications for PLWH, and in supporting patient adherence through pharmacy consultation programs, mandatory continuing education, professional training, the development and dissemination of continually updated clinical standards, and programs such as AIDS Education and Training Center (AETC) that provide high-quality HIV-dedicated training to providers such as doctors, nurses, pharmacists, and dentists. Expand the number of specialists available to serve PLWH.
- Continue funding programs such as the AIDS Drug Assistance Program (ADAP), Medi-Cal, Healthy Families, and the Children's Health Insurance Program that help subsidize the cost of medications. Continue to ensure these programs' wide accessibility to patients. Expand the number of candidates for antiretrovirals (ARVs) through relevant services such as substance abuse treatment, housing, transportation, and case finding, and provide services to support patient adherence at all levels.

Benefits Counseling and Insurance Issues

- Ensure that PLWH are aware of insurance benefits and other entitlements for which they are eligible, and that they are provided with all needed assistance to access such benefits. Work to overcome key barriers to entitlement and benefits access, such as bureaucratic and confusing paperwork; uninformed agency staff; and fear of potential immigration status problems.
- Provide expert benefits counseling for PLWH to help them navigate the changing landscape of public benefits, including Medicare Part D, Medi-Cal waivers, and the Consolidated Omnibus Budget Reconciliation Action COBRA) of 1985 laws.
- As Medicare Part D is implemented in California, ensure that PLWH are educated about their benefits and responsibilities, and that dual eligibles experience minimal

disruptions in their medications. Train benefits counselors, case managers, and others on how to ensure PLWH are enrolled in all eligible services and maintain medication and other services to the greatest extent possible.

Border Health Issues

- ❖ Develop improved systems to assess and respond to the migration of new HIV-infected individuals into California from other states and nations.
- ❖ Promote the continuity of care for the United States (U.S.)/Mexico border population, including both the transborder population that lives and/or works in the border area and continually travels between both countries, and the migrant population moving through the border region and throughout California.
- ❖ Train medical and social service professionals in the unique challenges of working in the border area, especially in the dual cultural approaches to accessing health and social services. Ensure providers are culturally and linguistically competent to work with the border population.
- ❖ Increase the level of outreach and education for PLWH in the border region, including education about HIV, information on the services available, and linkages to primary medical care and other services.
- ❖ Continue researching the health care needs of immigrants and border residents, as well as how best to coordinate care with Mexican providers and authorities.

Case Management Services

- ❖ Improve the quality of service access and coordination for PLWH by increasing the professionalism, relevance, comprehensiveness, and client sensitivity of case management services at all levels of care, and by expanding efforts to create and support integrated case management systems and definitions throughout California.
- ❖ Expand case manager training and education; ensure greater consistency in staffing; recruit greater numbers of self-disclosing HIV-positive and other peer case managers; increase bilingual case management capacity; reduce unreasonable client caseloads; and facilitate greater integration and consolidation of regional case management systems among social and medical service agencies.
- ❖ Seek a consensus definition of case management.
- ❖ Maximize the effectiveness of case management services throughout the state. Create better data systems to strengthen evaluation and improvement of case management. Support development of appropriate exit strategies from case management and greater self-reliance among clients.

Co-morbidities and Sexually Transmitted Diseases (STDs)

- ❖ Establish HIV testing as a standard of care in all STD clinics, and treat these clinics as key points of entry into the overall HIV/AIDS care system. Ensure that screening, diagnosis, and treatment of STDs is part of the HIV standard of care, with referrals to prevention services when appropriate.

- Strengthen the existing service system to better respond to the escalating epidemic of hepatitis C—including improved education, prevention, testing, and treatment, and link this system more fully to the existing HIV care system. Ensure hepatitis vaccination and treatment is part of the standard of care for HIV.
- Establish HIV counseling and testing as a standard of care for all persons with confirmed or suspected cases of tuberculosis (TB) in California as well as regular TB testing for PLWH at risk of acquiring TB.

Communities of Color Issues

- Ensure the availability of culturally appropriate, community-based services for all communities of color affected by HIV/AIDS in California, including African American, Latino, Asian/Pacific Islander, and Native American populations. This includes expanding the number of people of color in direct care and service positions at all levels of care and service, and ensuring greater availability of care services directly within ethnic neighborhoods.
- Place a greater emphasis on expanding the availability and utilization of preventive care services by communities of color, who—because of economic, language, historical distrust of medical institutions, or residency issues—often utilize health care services only for critical or emergency care needs. Develop more health promotion services targeting communities of color. Support programs that teach self-management and reduce dependency on social services.
- Examine the ways in which the existing system of HIV service and support will need to change or become more flexible to address those populations that are becoming more frequently affected by HIV. Ensure ongoing flexibility in the location and scheduling of care and services for these and other populations.
- Continue to address language, literacy, and cultural barriers to care for PLWH whose primary language is not English, particularly in terms of the severe lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific languages, including Cantonese, Tagalog, Vietnamese, Cambodian, and Thai.
- Reduce barriers to HIV-related health care for Native Americans living both inside and outside of reservations, including expanding culturally competent care and support services in city-based facilities. Coordinate services, wherever possible, with care funded through the Indian Health Service of the Bureau of Indian Affairs.
- Continue to promote outreach to and collaboration with community of color-based organizations and faith-based groups by larger health care institutions and CARE Act-funded providers, particularly as they serve as key entry points for bringing persons of color living with HIV/AIDS into the overall continuum of care.

Complementary Therapies and Treatments

- Ensure access to high-quality, affordable complementary therapies and treatments that reduce the side effects of HIV medications, promote wellness, and reduce stress. Examples of such therapies may include: acupuncture, acupressure, or

herbal treatments, with selection of treatments based on local and state regulations, agency programs, and identified client needs.

- ❖ Educate both patients and providers about the need to coordinate Western and complementary care to avoid harmful interactions and maximize benefits.

Corrections Settings and Incarcerated Individuals

- ❖ Ensure that all incarcerated individuals have immediate access to appropriate medical care, including referrals to specialists, pain management, diagnostic tests, and accurate information about their treatment options. Develop systems to ensure better accountability and higher quality health care within the California prison system, and to bring the quality of HIV/AIDS care and service in correctional settings to the level of community-based standards of care, including Public Health Service (PHS) treatment guidelines.
- ❖ Ensure that PLWH are able to take their medications as required, in coordination with meal schedules as needed, and that prison policies do not interfere with the ability for PLWH to take their medications. Ensure coordination of HIV services among different incarceration settings, and ensure continuity of care following prisoner transfers.
- ❖ Ensure that PLWH receive appropriate services in local jails and juvenile detention facilities. Protect the confidentiality of incarcerated PLWH, especially in juvenile facilities.
- ❖ Ensure the provision of transitional services with linkages to the community for PLWH being released from incarcerated settings. PLWH should always be released from prison with a supply of any prescribed medications, complete medical records, and linkages to all appropriate community services.
- ❖ Increase funding for transitional case management services for county and state correctional systems.
- ❖ Expand the participation of correctional and criminal justice experts on HIV planning bodies in California.

Dental and Oral Health Care Issues

- ❖ Ensure the full available of adequate and comprehensive oral health care services for PLWH across all regions and populations. Create a statewide mechanism for recruiting oral health dentistry fellows, and emphasize dentistry as a topic to be covered by AETC's provider training activities. Make new funds available to expand and create new dental and oral health services for PLWH through existing CARE Act titles.

Direct Emergency Financial Assistance

- ❖ Maintain the availability of direct emergency financial assistance services for low-income PLWH.

Employment Development, Placement, and Training Issues

- Support PLWH in their efforts to compete successfully for part-time, temporary, or full-time employment. Provide counseling, training, and other assistance needed to ensure job-related education, training, retraining, or trial work periods, applying federal guidelines if the individual is receiving disability benefits.
- Improve coordination among federal, state, and local government and private sector organizations that focus on habilitation, rehabilitation, and employment.

Families and Children

- Ensure children's access to comprehensive and coordinated, family-centered, and developmentally appropriate HIV medical and support services.
- Ensure comprehensive developmental evaluations and interventions to promote learning, participation in school, and youth participation in medication adherence. Improve family-focused assessment skills and develop treatment plans for families. Help families plan for the future through education about and improved access to permanency planning.
- Promote community planning efforts for multi-system interventions for families. Increase the capacity of agencies serving adults to assess family needs and facilitate care for children.
- Advocate with health care systems for supportive mental health and other psychosocial services for children affected by HIV, including HIV-negative children with HIV-positive parents.
- Increase resources for child care, both respite child care to enable access to medical and social service appointments for parents and other family members, and ongoing child care. Support CARE Act-funded agencies in offering on-site child care.

Food and Nutrition Services

- Ensure continued access to food and nutritional services, including nutritional counseling, for PLWH. Help HIV service providers identify and link to existing community food resources.

HIV Testing, Case Reporting, and Confidentiality

- Continue to improve links from HIV counseling and testing programs to HIV care and treatment services, and make referrals and linkages as seamless as possible for newly positive PLWH.
- Encourage PLWH to access the California Disclosure Assistance Program Services (CDAPS) if they want help with partner counseling and referral services.
- Continue to protect the confidentiality of all PLWH in California, particularly as reporting requirements related to HIV and AIDS diagnosis change in the future.

- Continue to provide training and resources to local health jurisdictions to implement any new laws or regulations related to HIV reporting, HIV testing, and linkages to care.

Home Health Care and Day Health Care

- Ensure continued access to home health and hospice care for PLWH, including long-term care, access to Residential Care Facilities for the Chronically Ill (RCFCIs) and specialized dementia care programs.
- Expand the availability of day and respite care services throughout California, and increase the availability of licensed adult day health care facilities, particularly in rural areas. Ensure that existing day and respite capacity is not lost.

Housing and Homelessness

- Ensure that PLWH, including families affected by HIV, are able to access a comprehensive continuum of housing services and resources, including emergency shelter, transitional housing, housing/rental subsidies, foster homes, congregate living facilities, skilled nursing facilities, board and care facilities, transitional housing for parolees and others released from prisons and detention facilities, clean and sober living environments, and housing for people with multiple diagnoses. Ensure that HIV/AIDS housing is available in the least restrictive form desired by each individual.
- Develop strategies and technical assistance resources to help communities' access additional housing resources for PLWH. Encourage and provide incentives for local jurisdictions to utilize U.S. Department of Housing and Urban Development (HUD) funding, and other housing funds as sources for building or converting low-income housing specifically for PLWH. Expand integration with Healthcare for the Homeless grantees and with local housing authorities.
- Ensure that care services are reaching the homeless, including those not in shelters or emergency housing. These men and women can be among the most difficult PLWH to reach, which means that additional efforts must be made in order to bring services to them, and to ensure that medical and other programs are fully accessible. Outreach and peer advocacy are essential components in this effort.
- Prevent homelessness and interrupted primary medical care through providing long- and short-term housing and outreach to those PLWH who drop in and out of care. Stabilize and maintain in care those most likely to be lost to care.

Immigration and Migration

- Ensure that comprehensive and culturally appropriate HIV/AIDS care and services are provided to all immigrant and undocumented persons in California regardless of their residency or migration status. Ensure that immigrants with HIV are educated about their ability to access health care and other services.

- Develop improved systems to better assess and respond to the extensive and continual migration that occurs within different regions of California, including between urban and rural areas, and within Hispanic/Latino and Asian/Pacific Islander migrant worker communities.

Legal Services

- Ensure that PLWH have full access to legal support and assistance services, including support with accessing benefits and insurance, combating and overcoming discrimination, wills and end-of-life issues, permanency planning for family members, immigration, and understanding their rights as employees.

Living Longer and Aging HIV-Affected Populations

- Examine the ways in which the HIV service system will need to evolve to confront the fact that many men and women with HIV and AIDS are living longer and growing older. Address the fact that the growing perception of HIV disease as a chronic, non-life threatening illness is affecting both the availability of resources and the ability to sustain existing systems of care.
- Ensure that as PLWH continue to live longer, healthier lives, that adequate medical attention and resources are focused on the new health problems beginning to emerge among these populations, including diabetes, lipodystrophy, heart disease, liver disease, manifestations of Hepatitis C, and preventive and restorative dental care. This includes health, psychological, and social impacts of aging as a person with HIV, including issues of isolation and lack of social interaction. Provide expanded cross-training, education, and enhanced resources, and more information on medication interactions and metabolic complications. Ensure that care and treatment resources continue to be available at a level commensurate with the growth in the overall population of PLWH to be served.
- Aging populations create greater needs for generalized preventive health services for PLWH, including an expanded emphasis on cardiovascular health, regular procedures such as breast and prostate exams, and ongoing patient health education in regard to self-care and non-HIV health needs. Provide greater levels of specialty care to meet increasingly complex patient needs.
- Expand the availability of residential-based services for PLWH who are very ill and who need the support of residential settings in order to start on ARV therapies with the hope of recovery. Expand opportunities for persons living longer with HIV/AIDS to participate in community activities, including more chances to socialize with others with HIV/AIDS, and more options to volunteer.

Managed Care and Medicaid

- Ensure that PLWH who are enrolled in managed care systems have access to the leading standards of care for HIV disease, and that the quality of care they provide is at least equivalent to community-based standards of care outside of managed care settings. Ensure that managed care organizations provide geographically

accessible and experienced HIV/AIDS service providers for all PLWH, and that existing regulations are enforced. Require that a clearly understood and easily accessible consumer grievance system be in place within all managed care programs.

- ❖ Adjust managed care capitation rates or create "carve-outs" where needed to reflect the full range and frequency of higher costs of service provision for PLWH. Ensure an adequate Medi-Cal capitation rate that includes drug treatment, outpatient medical and dental care, social services, and the risk of extreme inpatient care costs.
- ❖ Ensure continuation of Medi-Cal benefits for persons with HIV disease, and expand Medi-Cal in California to cover not only PLWH, but also PLWH who meet income criteria. Encourage the State of California to move forward with waiver requests and supportive legislation as both a humane and cost-effective approach to financing HIV/AIDS care.
- ❖ Ensure and enhance coordination between Medi-Cal and CARE Act systems, and between Medi-Cal and other systems of community care throughout California.

Men Who Have Sex with Men (MSM)

- ❖ Implement the *Framework for Gay Men's Health and Wellness*, as developed by CHPG.
- ❖ Address homophobia and stigma as a barrier to care for MSM. Ensure that culturally appropriate services for gay/bisexual men are accessible and available across the state.

Mental Health and Counseling Issues

- ❖ Ensure that PLWH are able to access appropriate mental health assessments and treatment programs, including psychiatric consultation and psychotropic medications. Ensure that such services make use of existing mental health service systems, and that they include patient psychiatric care, community-based outpatient treatment in individual and group modalities, short- and long-term therapy, support groups, crisis services, and residential treatment, in accessible and culturally appropriate modalities.

Multiply-Diagnosed Populations

- ❖ Assure that the complex needs of these individuals are addressed so that they do not slip through the cracks as health care systems focus more closely on cost efficiency and cost savings in light of managed care. Explore the possibility of integrated funding to support these services within a unified framework.
- ❖ Support the development of integrated and interdisciplinary models of care to ensure greater coordination among primary care providers, specialty providers, and case management and psychosocial services professionals. Increase the resources available to fund successful, effective integrated programs.

- Train providers in multi-disciplinary approaches to reaching and serving the multiply diagnosed. Increase cross-training opportunities for both mental health and substance abuse treatment professionals.

Peer Advocacy, Empowerment, and Self-Help Services

- Develop and implement programs that end social isolation among PLWH and that empower PLWH to take greater a greater role in influencing and controlling the quality of their lives and health care.
- Ensure the continued availability of peer advocacy services through which trained individuals provide direct service, support, and assistance to PLWH from comparable or compatible sociodemographic backgrounds. Provide support and supervision for peer advocates to help them manage their role as a service provider.
- Ensure the participation of members of specific populations, such as gay/bisexual men, women, young people, and people of color, in the development of services geared to these populations.
- Provide PLWH with the skills necessary to effectively contribute to local and regional planning and implementation processes, including making leadership training and technical assistance available on an ongoing basis.

Poverty as a Public Health Issue

- Address the fact that a growing percentage of HIV-related client needs and problems are rooted in poverty by developing effective methods to jointly address poverty and HIV issues in California. Increase opportunities to form and develop partnerships between HIV providers and poverty-related community groups and advocates in order to expand and deliver services for both populations.

Prevention with HIV-Positive Persons

- Continue to develop effective and comprehensive prevention services for PLWH. Ensure that such services are focused on empowering persons with HIV to protect themselves and others; that they are provided in culturally appropriate, respectful ways that take into account the emotional and mental health aspects of HIV/AIDS; and that they are coordinated with systems of care for PLWH.
- Ensure that prevention messages and interventions are tailored to PLWH as distinct and separate from prevention messages and interventions for negative individuals, and that they are, nonetheless, continually integrated and coordinated with HIV prevention efforts for HIV-negative individuals.
- Support disclosure assistance programs such as the CDAPS designed to support PLWH in disclosing their status to sex and drug using partners.

Research and Clinical Trials

- Include the broadest possible cross-section of populations affected by HIV/AIDS, including populations of color, adolescents and young adults, women, and injection drug users, in government-sponsored clinical trials programs, and expand the opportunities for persons with HIV from all economic, geographic, and cultural backgrounds to participate in clinical trials research. Support research on complementary and alternative therapies as an important strategy for exploring potentially promising new treatments for HIV disease.
- Continue to expand support for research into models of service delivery, models of evaluating effectiveness and efficiency in care delivery, models for ensuring greater client adherence to care appointments and to therapeutic regimens, service effectiveness, best practices, and the importance of cultural responsiveness in improving client adherence. Increase opportunities for collaborative interaction between researchers and providers at all levels of care. This includes broadening channels for disseminating and sharing research findings at the community level, and for finding ways to better incorporate research findings into community-based planning and program development. Support participation by HIV service providers in community-based research.
- Ensure that new advances in HIV-related treatment and care are quickly and continually incorporated into the care received by PLWH at the local level. Provide training opportunities for clinicians on the latest research results and how to incorporate them into clinical practice.

Rural Service Issues

- Address continuing HIV/AIDS service deficiencies and barriers in rural areas, including an overall lack of public health infrastructure, lack of transportation, housing, mental health, substance abuse treatment, or other support services or skilled service providers. Remedy the shortage of doctors, nurses, and other health care professionals qualified and trained in HIV care and other specialty care areas. Address stigma and confidentiality concerns as barriers to care in rural areas.

Stigma and Other Cultural Issues

- Continue to reduce service disparities by ensuring that HIV care providers relate to and understand the particular life choices, needs, and cultural backgrounds of their HIV affected patients, and that they reflect, to the extent possible, the cultural, linguistic, and lifestyle backgrounds of the clients they serve.
- Address stigma as a barrier to care through education and social marketing campaigns and support community institutions such as churches to address HIV/AIDS appropriately in their communities.

Substance Use and Addiction Treatment Services

- Increase the availability of harm reduction services at all levels, particularly needle exchange programs through which injection drug users have access to clean needles every time they use drugs. Fully incorporate harm reduction services into other HIV/AIDS service and care modalities, so that consumers are not unnecessarily lost to the system, and ensure a high quality of harm reduction services.
- Educate and support active substance users in adhering to complex HIV treatment regimens regardless of their current drug use profile, and ensure that they are provided with access to medical care, social services, and comprehensive treatment alternatives at all levels.
- Increase funding for all levels of substance abuse and addiction treatment. Eliminate wait lists for treatment. Ensure the availability of culturally competent substance abuse assessment and treatment programs for all PLWH who wish to receive them, through a continuum of treatment options including residential (medical) and non-residential detoxification, short-term and long-term residential care, and outpatient services.
- Ensure the availability of supportive services that help individuals achieve success in substance abuse, including transitional and supportive housing for individuals leaving treatment, transportation, mental health services, and job training and placement. Expand substance abuse–related service integration and coordination among providers, as well as development of expanded transitional "after-care" programs for HIV-affected men and women in substance abuse treatment.
- Support the development, evaluation, expansion, and dissemination of effective treatment for methamphetamine and other stimulant addictions. Disseminate best practices from culturally-specific programs such as The Stonewall Project in the City of San Francisco serving gay/bisexual men.
- Support the development and use of alternative addiction treatments such as buprenorphine. Support the use of office-based prescribed treatments including methadone and buprenorphine as appropriate for substance abuse treatment. Support research into other promising addiction treatments.

Systemic Barriers to Care

- Ensure culturally appropriate services are available for all PWLH. Support effective training in cultural competency for all CARE Act-funded programs and providers. Continue supporting community-based services and programs targeting specific communities or populations. Ensure translation services are available for all PLWH who need them.
- Provide agencies with the resources, training, and technical assistance needed to collect, enter, report, and analyze program data. Support coordination of multiple reporting requirements and the federal, state, and local levels to reduce the administrative burden on providers.

- Support the development of integrated and interdisciplinary models of care to ensure greater coordination among the primary care provider, specialty providers, and case management and psychosocial services professionals. Support agency mergers and collaborations when possible.
- Encourage integration of local planning and collaboration among all CARE Act grantees and other public and private funders in order to ensure maximization of available resources and development of a comprehensive continuum of care within each region.
- Encourage the data collection and analysis needed for quality management, including support for electronic medical records, and systems to minimize medical errors. Fund information technology to improve the quality of services for PLWH and incorporate it into best practices.
- Support professional development and training for HIV providers. Increase funding levels to help agencies retain qualified, experienced staff. Encourage agencies to develop policies and programs to counter staff burnout and reduce turnover.

Transgender Service Issues

- Address the needs of transgender PLWH in the design of service programs, including but not limited to outreach, primary care, substance abuse, gender transition therapies, mental health, and housing services.
- Provide training and support for providers to offer culturally appropriate services to transgender PLWH.
- Include representation of transgender individuals in epidemiological and data collection activities as well as community planning. Use appropriate gender categories for data collection and research.
- Conduct more research on the service needs and barriers to care for transgender PLWH.

Translation and Interpretation Services

- Encourage agencies to hire a multi-lingual, multi-cultural staff at every level of care to avoid the need for separate translation services whenever possible.
- Provide translation and interpretation services for providers who do not speak the client's primary language to communicate medical and support information. Ensure that translation and interpretation services are culturally specific. Reduce dependence on children or other family members for translation. Provide interpretation and translation to enable deaf and monolingual PLWH to participate in community planning efforts.

Transportation Services

- Ensure full access to comprehensive transportation services for PLWH, including access to a full range of transportation options, and subsidization of transportation

costs, including transportation suitable and accessible to persons with disabilities other than HIV.

Women

- Address the special needs and concerns of HIV-infected women including access to women-focused primary care, regular gynecological care, support groups, housing, transportation, and mental health counseling. Ensure providers are trained in the medical needs of women with HIV, including gynecological symptoms and opportunistic infections, or potential hormone interactions with HIV medications. Provide pre-conception counseling and comprehensive prenatal care to women and their partners considering pregnancy.
- Address domestic violence and stigma as barriers to care for women, and the isolation experienced by many women with HIV/AIDS. Provide peer-based programs to educate women about their health and promote self-empowerment programs for HIV positive women.
- Support the development of systems of care designed to address women's needs, including those of women with dependent children. Support increased participation by women in clinical trials.
- Ensure that all California pregnant women have early access to HIV diagnosis and treatment, including ARV therapy, along with strong protections of personal confidentiality and choice. Ensure implementation of prenatal guidelines through clinician education and training. Facilitate access to HIV specialists with expertise in preventing perinatal transmission.
- Continue to reduce the rate of perinatal HIV transmission to zero. Ensure continued comprehensive HIV education for clinicians to allow them to provide HIV education, testing, and interventions designed to reduce perinatal HIV transmission. Encourage labor and delivery sites to offer rapid testing to women who have not tested or sought prenatal care, referral to appropriate specialists, and obstetrical interventions designed to reduce mother-to-child transmission. Support policy development in hospitals to appropriately incorporate rapid testing into labor and delivery settings as part of the standard of care. Ensure that confidentiality is a high priority in perinatal settings.

Young People and Adolescents

- Ensure that, as more and more young people (18-24) and adolescents (13-17) are affected by HIV/AIDS, specialized service continuums are developed and refined for all youth. This includes non-traditional testing and outreach programs, specialized medical care services and clinic times that are tailored to young people and are easily accessible. Design services to reach high-risk youth, including gay/bisexual or transgender young people and homeless youth.
- Provide increased substance abuse services for young adults living with HIV, access to specialized mental health treatment services, availability of housing,

transportation, and social support services, and support for young adults transitioning out of incarceration settings.

- ❖ Increase efforts to encourage and facilitate expanded, voluntary HIV testing by young people. Provide specialized prevention interventions for young PLWH that utilize approaches and systems distinct from those focused on HIV-positive adults.
- ❖ Provide accurate, comprehensive pre-adolescent and adolescent sex education to prevent and mitigate the transmission of HIV and other STDs among young people.

California SCSN Process

The process used to develop the SCSN was comprehensive and inclusive, despite the short timeframe available for the project. It incorporated existing needs assessments and consumer input from each of the California EMAs, needs assessments, and program descriptions from the Title III-, Title IV-, and Part F-funded agencies, input from CHPG, a state-sponsored meeting to review a draft document and provide additional input, and extensive review by the Title II grantee. It is consistent with the most recent Title II Comprehensive Plan for California. PLWH were included in the process at every step. The list of all SCSN participants is included in Appendix A.

CDHS/OA initiated the statewide process upon receipt of the guidance from HRSA in April 2005 and used a process similar to that used to produce the 2001 SCSN. OA identified and hired the consultant, Laura Thomas, to write the SCSN in June 2005. In July 2005, OA sent a letter to all CARE Act grantees in the state of California informing them of the process. The letter covered the financial contributions requested from each grantee to support the process and requested that they submit copies of their most recent needs assessments, consumer input reports, and grant proposals to the consultant. The consultant read all of the submitted documents and incorporated their findings into SCSN.

OA provided additional information including the Epidemiological Profile, the most recent unmet needs assessment, and other data on the HIV epidemic in California. The consultant reviewed available reports and studies on HIV in California, such as those funded by the Universitywide AIDS Research Program (UARP), and submitted relevant sections of SCSN for review to content experts in areas such as correctional health and HIV in the U.S./Mexico border region.

CHPG is the statewide body charged with advising OA on issues related to HIV care and prevention. CHPG membership includes PLWH, service providers, local health jurisdiction staff, and community advocates. At least one-quarter of CHPG members are PLWH, including consumers of CARE Act services. CHPG provided input on SCSN, and used a small-group process to identify needs of PLWH in California, emerging trends or issues, and critical gaps in services. The identified needs have been included in this document. CHPG documents, such as the *Framework for Gay Men's Health and Wellness*, which was the result of several years of community input and planning, have been incorporated into SCSN as well. The list of members is included in the Appendix.

The SCSN consultant produced a draft incorporating the collected input from the CARE Act grantees, OA, and CHPG. The draft was sent to all CARE Act grantees in the state for review and comment. The draft was reviewed and revised at a statewide meeting of CARE Act grantees, planning council leadership, PLWH, representatives of the CDHS, including OA and the Department of Alcohol and Drug Programs. Not all grantees could attend the meeting, but a geographically representative group including all of the Title I EMAs and selected Title III and Title IV agencies were present. Rural areas, the

U.S./Mexico border area, adolescent programs, homeless service providers, and urban hospitals were all represented. PLWH were active participants in the meeting. The group added information on missing areas of need, proposed alternate wording for sections, recommended different organizational formats, and suggested other changes to make the document more descriptive of the needs of PLWH in California. Other grantees, particularly Part F grantees, provided written comments and input on the draft. The full list of grantees and additional meeting participants is included in the Appendix.

CHPG is "a combined HIV prevention and care statewide working group, provides community perspectives, advice, and recommendations to CDHS/OA in the planning and development of programs and allocation of resources."

A final draft was produced based on the collected input and review. That draft was extensively reviewed and approved by OA for submission to HRSA in accordance with the guidance. This document reflects the input of the many consumers, providers, clinicians, researchers, public health officials, and community advocates who participated in the process, as well as the most recent epidemiology and research available.

Epidemiological Profile of HIV/AIDS in California

California has the world's sixth largest economy and is home to 12 percent of the population of the United States. Over 35 million people live in California, and it continues to grow, increasing in population by six percent from 2000 to 2004.[1] It is an amazingly diverse state, encompassing major cities, extensive suburban stretches, an agricultural industry that feeds much of the nation, and beautiful natural environments. Some of the poorest and some of the wealthiest Americans live in California, as well as a large transient population, including tourists, migrant workers, and the homeless. California is known for Hollywood and the entertainment industry, sunny beaches, earthquakes, Silicon Valley, and tourism, but it also serves as a home and place of work to millions of residents.

California's cultural and ethnic diversity is unmatched by any other state: according to the 2000 Census, people of color are the majority of the population and Whites in the minority. Thirty-two percent of Californians are Latino, 7 percent African American, and 11 percent Asian/Pacific Islander.[2] According to the California Department of Finance, the racial and ethnic distribution in California shifted significantly during the 1990s. White Californians dropped out of the majority down to 47 percent. The Latino population increased from one-quarter to nearly one-third, and the proportion of Asian/Pacific Islanders grew by 25 percent. The African American population held steady and Native Americans grew to just over one percent.[3] Over one-quarter of California residents were born in another country, a much higher proportion that the 11 percent of Americans who are foreign-born, and 40 percent report who speak a language other than English at home.[4]

California is the third largest state by geographic area, and the largest by population. Fifteen of the 100 most populous counties in the United States are located in California, the most of any state.[5] This includes the largest county in America by population, Los Angeles County with 9,937,739 residents. The largest county in America by land area, San Bernardino County, covering 20,052 square miles, is also in California.

California is home to two of the first epicenters of the AIDS epidemic, San Francisco and Los Angeles, and 15 percent of all PLWH in the United States. California has the

[1] Census Bureau, http://quickfacts.census.gov/qfd/states/06000.html, accessed January 14, 2006.

[2] Census Bureau, op.cit.

[3] State of California, Department of Finance, Race/Ethnic Population Estimates: Components of Change for California Counties, April 1990 to April 2000. Sacramento, California, August 2005.

[4] Census Bureau, op.cit.

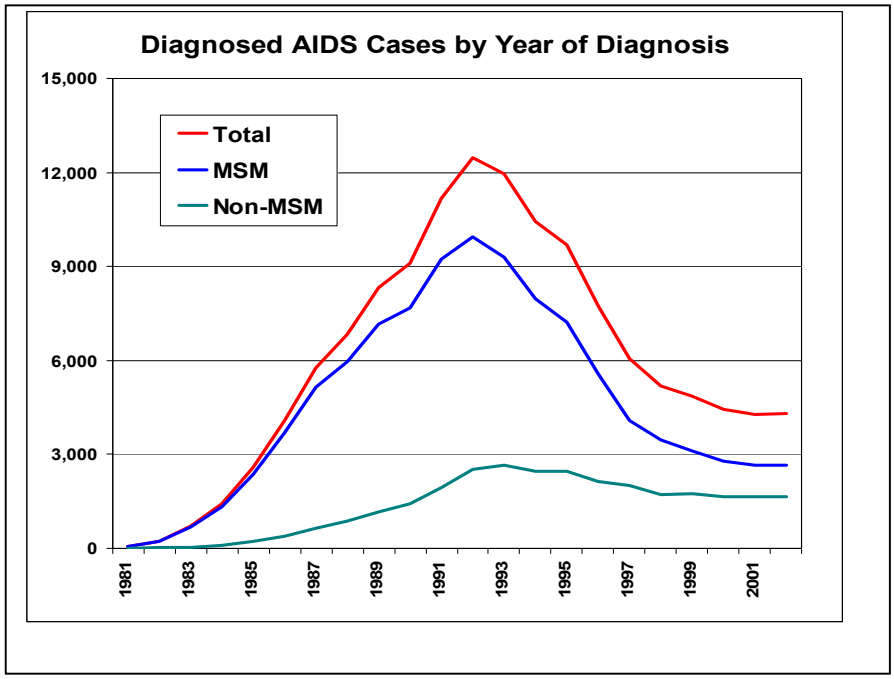
[5] Census Bureau, http://www.census.gov/Press-Release/www/releases/archives/population/004654.html, accessed January 14, 2006.

second largest number of people with AIDS, after New York State.[6] HIV in California affects every strata of society, and every corner of the state.

The data and information presented here are based on the AIDS and HIV cases reported to the California HIV/AIDS Case Registry through November 30, 2005. AIDS and HIV are both reportable conditions in California. HIV is currently reported using a non-name based coded identifier, although legislation has been introduced to report HIV using names.

Cumulative AIDS and HIV Cases

As of November 30, 2005, 139,094 AIDS diagnoses and 39,717 HIV infections had been reported in California. The epidemic in California is predominantly among gay/bisexual men and among Whites, although the proportions of cases that are women, heterosexual, and people of color continue to increase, and African Americans in particular are disproportionately represented. MSM have been the largest HIV transmission group in California since the beginning of the epidemic, and continue to comprise the majority of newly diagnosed cases of AIDS. White males, age 25 or older at diagnosis, account for most AIDS (N=73,531) and HIV (N=16,398) cases reported to date. Forty-two percent of individuals reported with AIDS are still alive. AIDS case reports peaked in 1992 in California, and have declined dramatically since then, due primarily to the success of ARV therapy and better prophylaxis for opportunistic infections. The decline in new diagnoses has been leveling off in recent years.

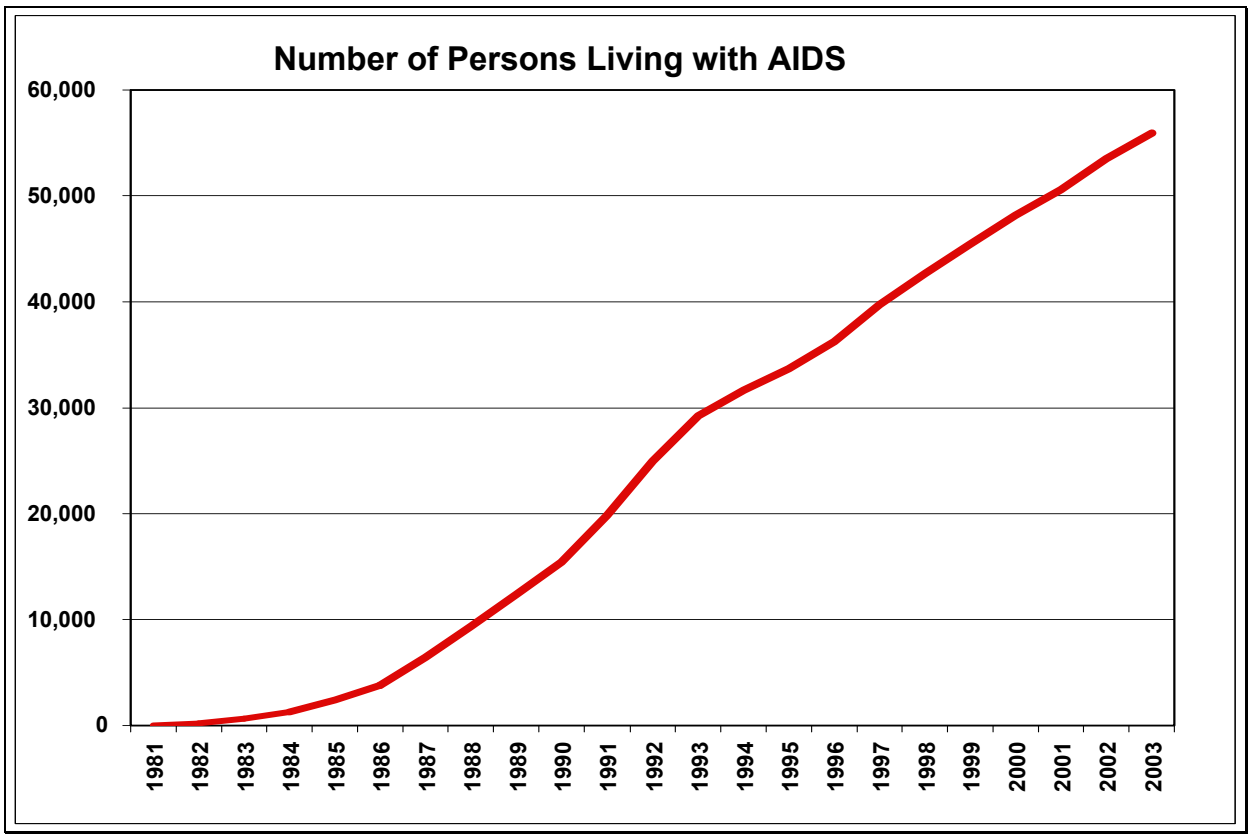


People Living with AIDS in California

The number of individuals diagnosed and reported with AIDS, and not reported as deceased, has grown steadily across all demographic groups since 1990; PLWH have

[6] Centers for Disease Control and Prevention, http://www.cdc.gov/hiv/stats.htm, accessed January 14, 2006.

increased by 263 percent since 1990. As of November 30, 2005, 57,961 adults were living with AIDS in California. Of those, 89 percent are men and 11 percent are women. The racial/ethnic breakdowns vary by gender. Whites (51 percent) and Hispanic/Latinos (29 percent) account for the majority of adult/adolescent men living with AIDS in California. Women living with AIDS in California are mainly African American (35 percent), Latina (30 percent), or White (30 percent).

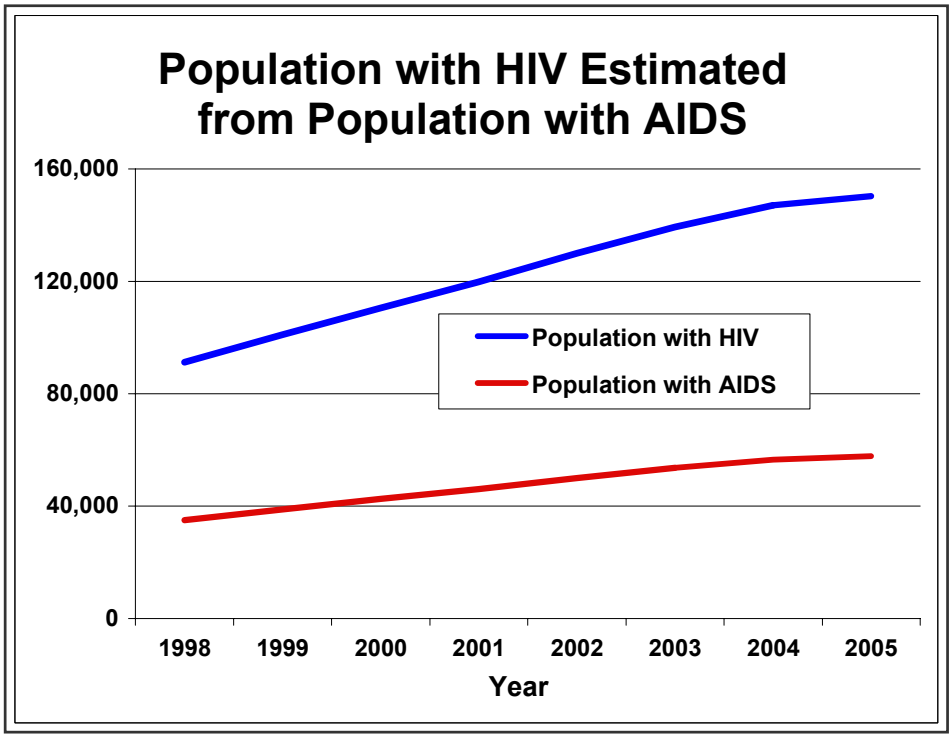


Source: A. Nakamura, California AIDS Registry, CDHS/OA.

The majority of individuals living with AIDS were between the ages of 30 and 50 when diagnosed. Forty-five percent of males and 40 percent of females in this group were diagnosed in their 30s. A smaller percentage, 16 percent of males and 21 percent of females, were diagnosed with AIDS during their 20s. MSM account for most of the individuals living with AIDS in California. Of the 51,690 men, 82 percent are MSM, including MSM who are also injection drug users (MSM/IDUs). Among women living with AIDS, 51 percent were exposed through heterosexual contact, and 32 percent through injection drug use.

People Living with HIV in California

In total, 39,692 adults and adolescents have been reported with HIV in California. HIV reporting is new in California, and the number of reported cases is still below the HIV prevalence estimated by OA. As shown in the graph below, the estimate, based on national data, is that the population of Californians living with HIV is 2.6 times that of people with AIDS. For those HIV cases that have been reported as of November 30, 2005, the demographics are similar to those with AIDS. The vast majority (84 percent) is male and most are White (52 percent) or Latino (25 percent). The racial/ethnic breakdown of women with HIV is 36 percent African American, 30 percent Latina, and 27 percent White. The majority of individuals, 42 percent of males and 35 percent of females with HIV were diagnosed in their 30s. One-fourth of the men and 31 percent of the women in this group were diagnosed with HIV in their 20s.



HIV exposure among those living with HIV in California is similar to that for AIDS cases. Among men, MSM and MSM/IDU account for 79 percent of cases. Women who are living with HIV were exposed primarily through heterosexual contact (44 percent) or injection drug use (23 percent). For approximately one-third of the women living with HIV in California, exposure falls into the Other/Undetermined category. For the majority of these cases, the known risk is heterosexual contact, but without the sexual partner's risk information they cannot be placed in the "Heterosexual Contact" category according to the Centers for Disease Control and Prevention (CDC) guidelines.

People of Color with HIV/AIDS

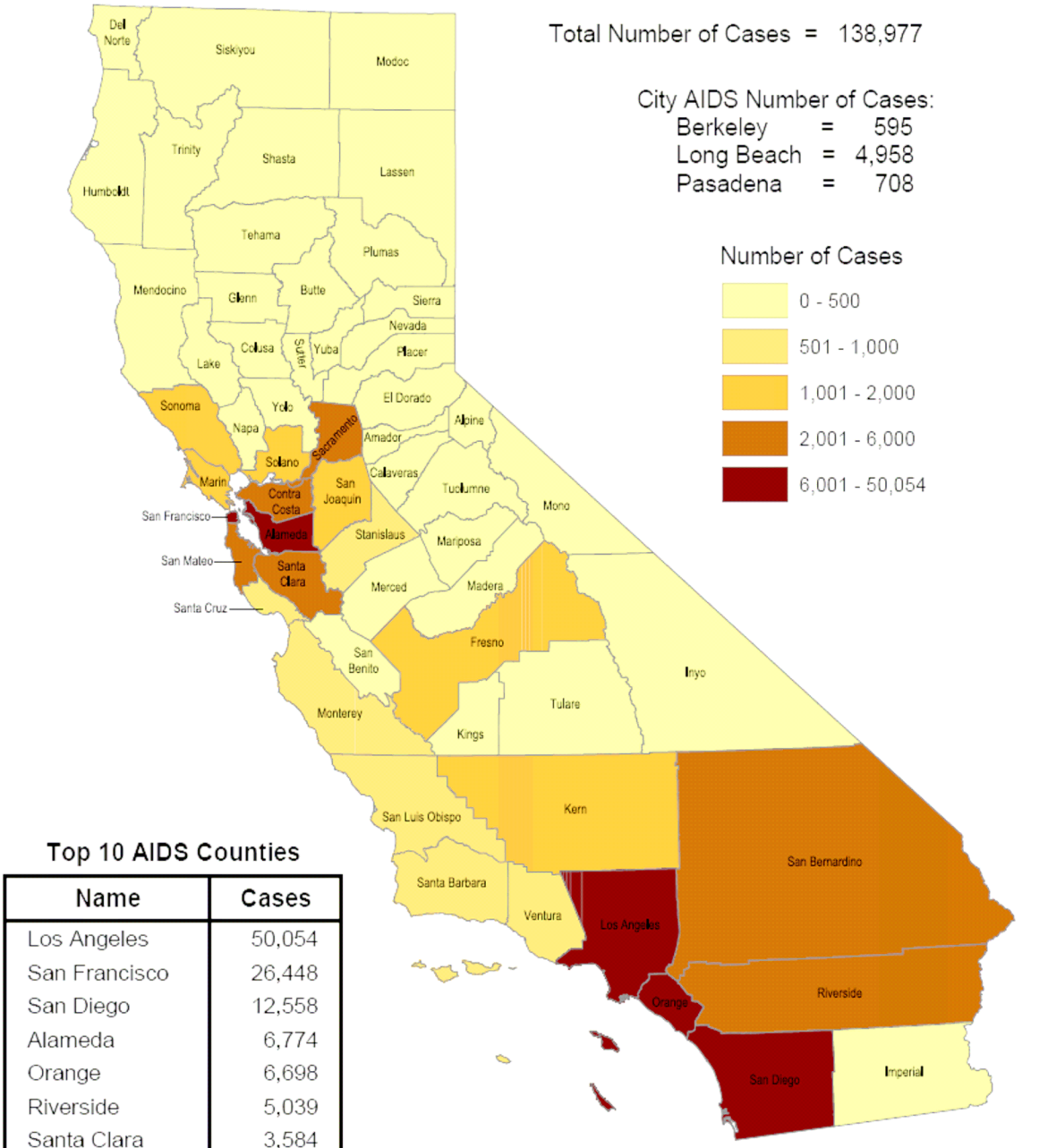
People of color in California continue to be heavily affected by the HIV/AIDS epidemic, and their proportion within the overall AIDS caseload is increasing. In 1988, for example, people of color made up less than 30 percent of all new AIDS cases reported that year. By 1997, the majority of new annual AIDS cases were occurring among

people of color populations, and by 1999, the percentage had grown to 55 percent of all new AIDS cases. People of color are 51 percent of all HIV cases reported as of November 30, 2005. African Americans in California bear a disproportionate burden of HIV disease. African Americans are only 7 percent of the total California population, yet 19 percent of those diagnosed with HIV, 18 percent of cumulative AIDS cases, and 20 percent of new AIDS diagnoses. For women living with HIV/AIDS, the disparity is even greater; fully 38 percent of all women living with AIDS in California are African Americans, versus only 17 percent of men.

Geographic Distribution of the Epidemic

California is a large and diverse state, and the HIV epidemic looks very different in different regions, counties, and communities. The AIDS epidemic in California began in San Francisco and Los Angeles, and most PLWH are still clustered in those two regions. San Francisco has by far the highest prevalence rate, with 1,149 PLWH per 100,000 population, and Los Angeles has the largest total number of PLWH, second only to New York City. California is home to nine Title I EMAs, the most of any state. No county has been untouched by HIV; even the sparsely populated counties in the northeastern part of the state have reported cases. As the agricultural counties of the Central Valley become more suburban and see rapid population growth, the numbers of PLWH grow as well. The map on the following page shows the geographic distribution of cases across the state.

AIDS CASES IN CALIFORNIA
CUMULATIVE AS OF NOVEMBER 30, 2005



Top 10 AIDS Counties

Name	Cases
Los Angeles	50,054
San Francisco	26,448
San Diego	12,558
Alameda	6,774
Orange	6,698
Riverside	5,039
Santa Clara	3,584
Sacramento	3,334
San Bernardino	3,310
Contra Costa	2,594

California Department of Health Services
Office of AIDS
HIV/AIDS Epidemiology Branch

California Estimate of Unmet Need for HIV Medical Care

OA estimated California's unmet need for HIV primary medical care, following the Unmet Need Framework guidance from HRSA. It found that 41 percent of people living with AIDS and 54 percent of those living with HIV, for a total of 47 percent of all PLWH, were not in care and had an unmet need for HIV medical care. SCSN addresses those unmet needs for primary medical care.

An individual with AIDS or HIV (non-AIDS/aware) was considered to have unmet need for HIV primary medical care when there was no evidence of any of the following three components of HIV primary medical care in a 12-month period (fiscal year [FY] 2003-04): viral load testing, CD4 count, or ARV therapy. Receipt of one of more of these three services is considered to represent met need for HIV primary medical care.

Each year the State develops the Title II unmet need estimate and works in conjunction with California's nine EMAs to help them develop the Title I estimate using the Unmet Need Framework designed for measuring unmet need. The Unmet Need Framework was developed by the University of California, San Francisco, to assist EMAs and states in assessing unmet need. The framework uses locally available data on *population size* and *care patterns* to estimate the number of individuals with unmet need.

This focus on PLWH who know their status but are not in care has a legislative basis. The 2000 Amendments to the CARE Act require each Title I and Title II program to:

- "determine the size and demographics of the population of individuals with HIV disease," and
- "determine the needs of such populations, with particular attention to both individuals with HIV disease who know their HIV status and are not receiving HIV-related services" and "disparities in access and services among affected subpopulations and historically underserved communities."

To develop the unmet need estimate, OA matched and unduplicated individuals from ADAP, Medi-Cal, Kaiser Permanente, and the HIV/AIDS Reporting System (HARS). HIV/AIDS status was identified, need for HIV medical care was determined, and county codes were used to identify the EMA where the individual received care, was enrolled, or diagnosed. The nine California EMAs each received the matched HARS, ADAP, and Medi-Cal records for their specific counties. They matched this data with their local care and HARS data sets to identify additional HIV/AIDS cases and receipt of care services. After matching with their own data sets, EMAs send their final matched data back to OA, allowing OA to ensure that their Title II estimate includes all clients from the local level. Veteran's Administration (VA) data from HRSA are used to augment the public care estimate by including the number of individuals receiving HIV primary medical care through VA facilities in the state. The estimate from 2003 is shown below.

Unmet Need Framework for California

Input	Value	Data Source
Population Sizes		
A. Number of people living with AIDS in calendar year 2003.	55,750	2003 CDC prevalence estimate
B. Number of PLWH (non-AIDS, aware), recent time period in calendar year 2003.	45,000	2003 CDC point estimate
Care Patterns		
C. Number of people living with AIDS who received the specified primary medical care services in 2003.	32,876	HIV/AIDS Case Registry, ADAP, Medi-Cal, Kaiser Permanente, VA
D. Number of PLWH (non-AIDS, aware) who received the specified primary medical care services in 2003.	20,653	HIV/AIDS Case Registry, ADAP, Medi-Cal, Kaiser Permanente, VA
Calculated Results		**Calculation**
E. Number of people living with AIDS who did not receive specified primary medical care services (quantified estimate of unmet need among people living with AIDS)	22,874	= A – C
F. Number of PLWH (non-AIDS, aware) who did not receive specified primary medical care services (quantified estimate of unmet need among PLWH, non-AIDS)	24,347	= B – D
G. Total HIV positive/aware not receiving specified primary medical care services (quantified estimate of total unmet need)	47,221	= E + F

Cross-Cutting Issues and Goals

California's first SCSN in 1998 described how the size and diversity of the state of California presents unique and daunting challenges to planners of HIV care and services. Since then, California has become an even larger, more diverse, and more culturally rich state, and, as in our previous SCSNs, HIV/AIDS programs in California still must be designed to serve exceptionally varied groups and communities with specifically targeted programs, while reaching large populations in urban and suburban areas, and far-flung populations in rural and frontier communities.

Programs must also serve communities and groups that have widely differing needs, while linking and integrating these services among a wide variety of public and private sector providers. The high level of poverty, as well as the lack of health insurance, further complicates the effort to deliver effective, comprehensive services to persons with HIV. The California economy has struggled in the last few years, leaving cities, counties, and towns with fewer resources.

California's success in meeting and overcoming many of these challenges has led to a series of comprehensive care systems that meet many of the basic fundamental health and psychosocial needs of PLWH in our state. Community-based organizations and local health departments form the backbone of the service delivery system. California has made significant progress in providing access to basic medical services and new combination drug therapies, as well as basic medical services that are linked through a network of supportive services that help meet the physical, emotional, and practical needs of PLWH. We have also tried to create a system of greater access to services for a wider range of emerging populations, and have expanded outreach that has brought new individuals and families into treatment earlier.

Future Challenges

For California, the mark of progress achieved nearly always remains only a benchmark against which to measure future accomplishments. We still have a long way to go in guaranteeing full access to all needed services for all Californians affected by HIV, and we have much work to do to ensure that all residents of our state have access to services that consistently meet their health and social service needs in ways that respect their culture, language, and identity. California CARE Act grantees continue to implement HRSA’s principles for CARE Act-funded programs. Significant gaps remain in our system of care, despite our best efforts, and much work remains to be done in ensuring access to quality HIV/AIDS care; developing new approaches to integrating services; maximizing resources; and bringing people with HIV who are aware and unaware of their serostatus into care. Throughout California, communities, agencies, and local and state health jurisdictions strive to understand emerging HIV-related needs, evaluate the impact of CARE Act funds and make needed improvements, and continue to revise care systems to meet on-going and emerging needs.

HRSA Principles for CARE Act Programs:

- Revise care systems to meet emerging needs.
- Ensure access to quality HIV/AIDS care.
- Coordinate CARE Act services with other health care delivery systems.
- Evaluate the impact of CARE Act funds and make needed improvements.

One of the challenges to be faced over the next five years will be the implementation of the reauthorized CARE Act. Although reauthorization legislation has not yet been passed, it has the potential to make sweeping changes in the continuum of care for PLWH in California. Some of the proposed changes, such as the exclusion of Title I cases from the calculation of Title II base funding, would result in an immediate loss of nearly $20 million for California and would have a devastating impact on PLWH. The proposed transition to including HIV data in the funding formula, if implemented before California has fully transitioned to a functional name-based HIV reporting system, could result in a major loss of funding. Elimination of the provisions that protect jurisdictions from severe funding cuts would destabilize long-established systems of care and result in significant increases in unmet needs for PLWH and the number of people who are not in care. Other proposals, however, such as the one to move from the current ten-year weighted case band to actual living AIDS cases as the basis for formula allocations for Titles I and II, have the potential to rectify funding disparities and provide California with funding based on the actual number of PLWH in the state.

California faces both the promise and the challenge of a population of PLWH who are living longer. While this is a very welcome challenge, it puts added pressure on the system of care to adapt to meet the needs of an aging population of long-term survivors. PLWH with improved health are looking for education, jobs, training, and sometimes new career paths. It is important to help them reduce their reliance on the public care system, and to ensure that they maintain or improve their benefits and income in the process. PLWH are also having children, going back to school, or making other important life changes. The system of care must be able to help people exit it when CARE Act-funded services are no longer needed, just as it helps people enter it. Those PLWH who have not seen improved health will continue to be served, and as people age, they will need health care and other services that address any age-related health problems as well.

Gaps and Barriers

This document describes gaps in services for PLWH in California, the disparities experienced by various populations, and the barriers to care throughout the state. Gaps include missing or inadequate services, and are experienced by those who are not in primary medical care for their HIV, those who are not accessing services, and those living with HIV who are getting most but not all of their needs met. Disparities occur when a population or community faces greater needs, gaps, or barriers than other populations, or has uneven access to care. Barriers are factors that prevent individuals from accessing care.

The continuum of care for PLWH in California began when the first cases were identified in 1981 and has developed into a comprehensive systems of HIV care. It has succeeded in providing life-saving medical care and medications and helping to maintain the quality of life for thousands. Community planners and public health systems have identified gaps and barriers and addressed them, creating culturally competent, accessible services throughout the state. The system of care continues to grow and improve to offer higher quality services to the increasing numbers of PLHW, but that progress is threatened by shrinking resources and growing costs. Gaps, disparities, and barriers continue to exist, and in some instances may be growing. People with HIV may not all have their basic survival needs met, much less other health and social services.

Overarching Issues and Needs

Primarily because of the continuing efficacy of new drug treatments, PLWH in California are to living longer and healthier lives. While this has brought about a welcome decline in the number of AIDS-related deaths, it also means that more PLWH than ever before, including both CARE Act consumers and all people with AIDS. Ensuring that a longer lifespan is a welcome change, rather than a daunting challenge, remains one of the key goals of California's CARE Act-funded service system.

The key overriding need among California's HIV/AIDS service providers is to make certain that CARE Act services are available, accessible, and culturally and linguistically appropriate across all populations and service categories, and that we come as close as possible to HRSA’s goal of access to quality HIV care for all. This is both increasingly important and increasingly challenging as the population of CARE Act-supported PLWH in California are more likely to be poor, homeless or marginally housed, and multiply diagnosed. The Unmet Need analysis shows how far we have to go to achieve this.

The existing system of HIV service or support needs to continue to adapt its way of doing business in order to effectively address the emerging needs and increasing complexity of care for expanding HIV-affected populations such as the homeless, those with multiple diagnoses, women and single mothers, people of color, IDUs, young people, people in correctional settings, people with HIV and hepatitis C co-infection, and residents of rural communities. Many providers have been successfully reaching those populations since the beginning of the epidemic, and they need to share their expertise with providers who are just beginning to serve them. Each of these populations tends to access health care later in the disease process, and continues to face the stigma still associated with HIV/AIDS and HIV risk behaviors in society at large, a stigma that remains a barrier to accessing services and participating in the continuum of care. Each affected population requires a specific, tailored, and uniquely comprehensive set of services in order to ensure an effective continuum of care that meet their full range of needs, and provide specialized and appropriate service access.

The capacity for enhanced evaluation across the entire system of care must be expanded in all regions of California, including across all CARE Act titles and systems

of care, and throughout the state of California as a whole. Expanded data collection will allow agencies and jurisdictions to more quickly and accurately identify service gaps and deficiencies; to produce meaningful data that allows for effective assessment of the quality, impact, and outcomes of services; and to plan resource allocation scientifically. Evaluation should also be expanded to include reliable means of identifying and quantifying the number and nature of PLWH who are not in care. This goal is closely related to an expressed need for enhanced, standardized, system wide program and outcomes evaluation systems that establish realistic, comprehensive assessments of services, and that allow for cost/benefit, utilization, and client outcome analysis throughout the system.

Increased resources could address nearly all of the service gaps in this section. Those gaps have not yet been addressed, which speaks to the unavailability of the resources of time, funding, staff, or expertise to fill them. Over the last five years, California has faced cuts in Title I funding, inadequate increases in Title II funding, few new Title III clinics, and the end of several Special Projects of National Significance (SPNS) grants. Other resources have not increased, as the economic downturn has eroded local and state budgets. California has faced an energy crisis, job losses in the Internet and technology sectors, and well-publicized budget deficits leading to funding cuts in many public sectors. Services that PLWH need in many aspects of their lives have been cut, including support for health care and substance abuse treatment, public transit, housing, employment, and public benefits.

At the same time, the costs of providing services continue to increase, as do salaries, rents, insurance, and business overhead. California has some of the highest health care costs in the country, as measured by the Medicare Cost Index.[7] The cost of living and of providing housing and medical care is much higher in California than most other parts of the country. The four most expensive metropolitan areas in the country for medical care are in California, as measured by the Medicare Wage Index, a national measure developed by the federal government to determine the relative cost of providing medical services. The cost to provide one hour of primary medical care is higher in the City of Oakland than almost anywhere else in the country; fewer units of services can be provided for the same funds.

The number of people turning to CARE Act-funded services is higher than it has ever been, and the number of PLWA continues to grow in California. Those who have been living with HIV/AIDS since early in the epidemic are facing increasingly complex medical needs. Larger numbers of PLWH are multiply diagnosed with mental health and substance abuse issues and need more intensive services. This “perfect storm” of more people with more complex needs in an environment of increased costs and decreased resources has led to gaps and unmet needs developing anew, despite the

[7] Center for Medicaid and Medicare Services; *Proposed Changes to the Hospital Outpatient Prospective Payment System and Calendar Year 2005 Payment Rates*, Published at the Federal Register. August 16, 2004. Addendum H: Wage Index for Urban Areas.

resourcefulness and creativity of the many dedicated professionals and community members working to improve conditions for PLWH in California.

Reauthorization of the CARE Act has the potential to exacerbate the current problems if it results in fewer resources for California. A reduction in any one area has an impact on other areas, such that a loss in one EMA results in increased pressure on the services in nearby EMAs, as PLWH relocate to maintain access to care. The current allocation formula relies on an outdated ten-year weighted case count that ignores the presence of the many people with AIDS still living after ten years and significantly underestimates the number of people actually in need of services in the state. Proposed revisions to the Title II base allocation could reduce funds by $19 million, and using HIV data in the funding formula too soon could cost the state more than $50 million. The fiscal and programmatic impact of reauthorization is unknown, but has the potential to be dramatic and destructive to our system of care, and turn emerging gaps into gaping holes in the system of care.

As noted in our last SCSN, if the culture and diversity of California makes this a challenging place in which to forge and implement an effective system of services, then the range, depth, and complexity of our populations also make it an ideal site in which to develop creative and effective service models that respond to a diverse human community. If HIV has brought struggle and tragedy to California, it has also brought a unique spirit of community, enterprise, and partnership to the fight to conquer it. The existing system of HIV/AIDS care in California provides a model for the provision of community-based care in other health and social service areas. To assure equitable and quality care for all Californians, efforts must be made to raise other social issue and disease responses up to the level of HIV/AIDS, and not drop the level of support for HIV to a lower common denominator in which individuals do not receive the proper levels of community-based care, support, advocacy, and assistance they need and deserve.

The following list will illuminate some of the critical ways in which our state continues to face the most important challenges that lie ahead, while developing new ways to meet and overcome those challenges. It contains a non-prioritized list of overarching principles or values for HIV/AIDS care and services in California over the coming years, based on findings that have a broad consensus among HIV/AIDS providers and PLWH throughout the state. To be consistent with the guidance from HRSA, the list includes broad goals that are not prioritized. Some issues, gaps, or goals may be more relevant in some parts of the state than others; this list is intended to incorporate all of them into one document, leaving it to local planners and providers to determine which ones are the most essential or pressing for that area, using local and state data and community input in conjunction with this document.

Overarching Goals

- To provide to all PLWH in California the services necessary to sustain and support their health and quality of life, regardless of income or ability to pay, and across all

stages of illness, by maintaining and enhancing California's community-based system of HIV/AIDS care.

- To give all PLWH immediate access to high quality, culturally competent HIV primary medical care and treatment, including medications.
- To deliver HIV/AIDS services in California in an equitable, client-centered manner, that respond sensitively and appropriately to client age, gender, cultural group, language, sexual orientation, income, region or residence, family status, health status, incarceration status, and legal residency status.
- To ensure that HIV/AIDS services in California are delivered by experienced, competent, and fully trained providers who are knowledgeable about and responsive to their communities, and who understand and represent, to the extent possible, the cultural, linguistic, and community backgrounds of the clients they serve.
- To expand the participation of PLWH at all levels of HIV/AIDS planning, needs assessment, systems design, service implementation, and evaluation in California; and enhance opportunities and incentives for this participation.
- To maximize the number of PLWH who are aware of their status by supporting expanded targeted HIV testing efforts and linkages into care.
- To reduce new HIV transmissions by expanding effective prevention services for PLWH.
- To increase evaluation efforts and approaches that allow us to better assess the quality of care provided to PLWH, and to better document the outcomes and impacts of HIV care and services on the lives and health status of PLWH. To continue to evaluate the services and interventions and to use the evaluation data to improve and expand services to meet new and emerging needs as well as long-established needs. To use epidemiologic data and research findings to design and target services to those most in need.

Specific Care and Treatment Goals

This section describes the issues, concerns, and barriers related to specific services, populations, or issues, and identifies the goals for each area. In each area, the issues and needs are described, followed by a bulleted list of the relevant goals or principles for the state of California.

Access to Care

The most recent results show that there are an estimated 100,750 PLWH (who are aware of their status) in California. Of those, 53,529, or 53 percent are in primary medical care; with 47,221 or 47 percent out of care. Those out of care include an estimated 22,874 people living with AIDS, and 24,347 living with HIV, non-AIDS. The process of estimating the numbers of people not in care is described in the Epidemiology Profile section.

Some of the reasons why PLWH are not in care have been addressed in other sections of this document (stigma, homelessness, substance abuse, mental health, rural issues, and communities of color). Outreach helps find those who are newly diagnosed but not yet linked to care, as well as those who have been lost to care. Outreach and culturally competent services can help re-engage PLWH in care. More work needs to be done to determine the optimal service designs to bring people into care, and more resources need to be identified to support expanded program capacity.

Current resources are stretched to meet already identified needs, and increasing the population of people in care will require additional funding, staffing, and service capacity. Bringing one set of PLWH into care at the expense of services for those who have been in care defeats the intent by potentially creating a new set of PLWH who are not in care. Everyone with HIV/AIDS deserves to be in care, and the system will expand to meet the needs if more resources are available. Reductions in funding, such as those that would result from many of the proposed CARE Act reauthorization changes, will harm ongoing efforts to bring more people into care, and will instead lead to more PLWH being denied care.

In many areas, PLWH may not access HIV services because they do not know that services are available to meet their needs. PLWH may be unaware of how or where to access or obtain services, or that services may be available to them for low or no cost. To ensure full access to care, it is vital that HIV service providers publicize their programs both within the health and social service community and to the general public at large. However, these outreach efforts require additional resources that HIV programs often lack. Trained community health outreach workers can make a difference in educating people about the services available and assisting them in entering care.

Goals

- Fund and support outreach services for PLWH. Train community health outreach workers in effective outreach methods.
- Conduct ongoing research to identify and determine the service needs of those not in care and the barriers that are keeping them out of care. Identify and address the root causes of why they are not in care.
- Design and support services to bring PLWH into care and produce better health outcomes. Expand targeted outreach programs to find those who have been lost to care as well as those newly diagnosed.
- Identify or develop additional funding streams to support expanded program capacity for those who are currently not in care.

Ambulatory/Outpatient Medical Care and Drug Therapies

Ambulatory/Outpatient Medical Care

Despite significant successes, too many people with HIV in California still lack access to adequate HIV medical care. The Unmet Needs analyses for each Title I area have estimated that Unmet Needs range from 60 percent[8] and 20 percent[9] of PLWH are not currently in medical care. For the state as a whole, an estimated 47 percent of PLWH are not in medical care, as determined by using the HRSA Unmet Need Framework described above.

The reasons include insufficient funding for medical care, high rates of uninsured PLWH, inadequate transportation services in rural areas, lack of stabilization services such as housing for the homeless, a shortage of providers who speak a language other than English, and, in some areas, a shortage of physicians who are knowledgeable regarding HIV treatment and PHS standards of care.

Despite the availability of training opportunities for primary care physicians on emerging HIV issues and treatments, not all physicians or health care providers are able or willing to take advantage of these opportunities. The lack of adequately trained HIV care providers can result in a less than optimal quality of care that may impact the health of some patients. A recent Pacific AIDS Education & Training Center (PAETC) needs assessment found that even high-volume medical providers working in CARE Act-funded clinics in urban areas wanted more training on ARVs, managing side effects, viral resistance testing, and new treatment innovations.[10] Providers also wanted more information on working with women, aging populations, Latinos, and African Americans.[11]

[8] Orange County EMA Title I Application, 2005.

[9] San Francisco EMA Title I Epidemiology Report, 2005.

[10] PAETC Region-wide Needs Assessment, Fall 2004.

[11] Ibid.

The lack of availability of a basic medical service, such as access to an HIV specialist physician, means that some people with HIV will not be assured the most up-to-date treatments or that critical health conditions may not be diagnosed and treated in a timely manner. It is critical that HIV service systems be able to provide access to medical specialists and psychosocial providers who are trained and experienced in providing HIV care. Access to such care can sometimes mean the difference between an individual receiving adequate or inadequate care.

Primary care that is integrated with mental health and substance abuse treatment remains a gap across the state. PLWH with concurrent medical, mental health, and substance use conditions need coordinated care to produce the best health outcomes. Case conferences, shared client records, or cross-training can help integrate care. There are good models of integrated care for multiply-diagnosed PLWH in the state which could be replicated in other areas, and best practices shared with other providers.

Pain management is a critical component of HIV primary care. HIV-related conditions can often be extremely painful, and failure to adequately address the individual's pain management needs can create unnecessary suffering in the lives of people with HIV. Physicians should be trained to employ emerging and alternative approaches to pain management. Pain management for people with current or past opiate addictions may be particularly complicated and needs to be treated by providers skilled in working with that population.

Increased use of ARVs has greatly improved the health of many PLWH, but it has also led to increased rates of drug resistance. This can limit treatment options and complicate medical care. Genotype and phenotype tests can give clinicians and patients the information they need to make good treatment decisions. The tests are expensive, but essential for quality medical care for many PLWH. New HIV medications must continue to be developed, with fewer side effects, greater efficacy, and different resistance profiles. Ultimately a cure for HIV disease is what is needed most of all, but one is not yet on the horizon.

Medication Assistance

Most HIV-infected Californians can access a relatively large safety net for HIV medications compared with many other states and other diseases. A high proportion of PLWH in California use ARV therapy. Both Medi-Cal and ADAP formularies include all medications in the federal PHS HIV treatment guidelines. Increasingly, however, private health care plans are placing more financial responsibility and limitations on the insured individual, which means that people with HIV who have private insurance cannot always afford all medication treatments they need through that type of coverage. However, if they meet eligibility criteria, ADAP can assist with prescription coverage for HIV medications when private heath insurance is limited.

The impact of Medicare Part D implementation is yet to be fully known, but it will result in increased costs for many of the dual eligible (those eligible for both Medicare and Medicaid) PLWH in California. There is also concern that the formularies of the Part D pharmaceutical providers may not include all of the medications needed by PLWH. The financial impact on ADAP is unknown, but it may increase the pressure on limited funds if formerly insured PLWH need to rely on ADAP to make up for Medicare Part D inadequacies.

Goals

- Continue to make the availability of comprehensive, high-quality, and culturally competent primary medical care the first priority within the spectrum of CARE Act-funded care within the state of California. Ensure the universal availability and subsidy of all appropriate new and existing medications and drug treatment combinations, for all eligible persons with HIV who are deemed medically appropriate. Support programs that help and empower clients to understand and adhere to complex medication regimens, in order to maximize the benefits these treatments can provide.
- Ensure continuing professional competence in prescribing and monitoring medications for PLWH, and in supporting patient adherence through pharmacy consultation programs, mandatory continuing education, professional training, the development and dissemination of continually updated clinical standards, and programs such as AETC that provide high-quality HIV-dedicated training to providers such as doctors, nurses, pharmacists, and dentists. Expand the number of specialists available to serve PLWH.
- Continue funding programs such as ADAP, Medi-Cal, and Health Families that help subsidize the cost of medications. Continue to ensure these programs' wide accessibility to patients. Expand the number of candidates for ARV therapy through relevant services such as substance abuse treatment, housing, transportation, and case finding, and provide services to support patient adherence at all levels.

Benefits Counseling and Insurance Issues

HIV-related benefits include a broad array of options, sometimes with confusing eligibility requirements. Without knowledge and experience, it can be difficult for individuals to successfully navigate this system. In some communities, trained benefits counselors are available to explain services and advocate for clients. However, benefits counselors are not available to serve all clients. Additionally, frequent turnover among benefits counselors may mean that they may not always be fully aware of all available benefits and current eligibility criteria. Some clients may not access available benefits, and these benefits may be jeopardized or inadvertently lost. Getting eligible clients enrolled in programs such as Medi-Cal can take the pressure off of CARE Act-funded services, so access to benefits counseling helps both the individual and the system of care.

As in other public service systems, there are often duplicative intake processes and forms to be completed when people are entering and using the system of care. Clients may also be required to re-apply for public benefits or to re-establish eligibility for benefits or services on a monthly or quarterly basis. While these processes are part of any complex system of care, they increase the difficulty of accessing and maintaining care. For some persons seeking HIV services, these processes are barriers.

Medicare Part D, the new Medicare drug benefit, offers expanded medication access to some PLWH and limits the access for others. It is a complicated program, requiring informed client choice of benefit providers, navigation of a new and complex bureaucracy, and additional costs for many PLWH covered by the program. It is still being developed and implemented by the federal government and the private pharmacy benefits groups. California is in the process of training case managers, benefits counselors, and ADAP eligibility workers on Medicare Part D. Additional training and education will continue to be needed as Medicare Part D is implemented.

It is vital that PLWH who have private health insurance are informed of health insurance continuation benefits. There are two publicly funded insurance continuation programs in California, CARE/Health Insurance Premium Payment (HIPP) and Medi-Cal HIPP, which pay health insurance premiums for those who are eligible and who are unable to pay the premiums themselves. If individuals allow several months to pass without electing to continue health insurance benefits, the opportunity to receive coverage through these programs is lost, and public health benefits must fill the gap. This situation also emphasizes the critical need for qualified benefits and insurance counseling.

Goals

- Ensure that PLWH are aware of insurance benefits and other assistance for which they are eligible, and that they are provided access such benefits. Work to overcome key barriers to assistance and benefits access, such as bureaucratic and confusing paperwork, uninformed agency staff, and fear of potential immigration status problems.
- Provide expert benefits counseling for PLWH to help them navigate the changing landscape of public benefits, including Medicare Part D, Medi-Cal waivers, and COBRA laws.
- As Medicare Part D is implemented in California, ensure that people with HIV/AIDS are educated about their benefits and responsibilities, and that dual eligibles experience minimal disruptions in their medications. Train benefits counselors, case managers, and others on how to ensure PLWH are enrolled in all eligible services and maintain medication and other services to the greatest extent possible.

Border Health Issues

Mexican nationals and Mexican Americans are the largest segment of Latinos, the largest racial/ethnic group in the state, which is composed of a mix of ethnic groups and cultures. Among Mexican immigrants, an increasing number are indigenous peoples, many of whom are not fluent in either English or Spanish. Most immigrants travel through the California/Mexico border area, and many choose to remain. The California/Mexico border extends across the southern edge of the state. It is one of the busiest land-based border crossings in the world. Along the U.S./Mexico border, many Latinos travel back and forth for work, family, or personal reasons. Many people making these crossings are traveling back and forth across the border several times in one year or even in the same month. There are minimal health services along the border, leaving many local residents without access to primary medical care. Health care services are not well coordinated across the border, resulting in people receiving varying levels of care and contradictory medical advice. Some Latinos prefer to access health care in Mexico, due to their familiarity with the culture of health care there. Border area residents, especially in San Diego County, have high rates of uninsured and unemployment, along with high poverty rates.

Services for PLWH must be coordinated to assure continuity of care, of medications, and of prevention messages on both sides of the border. Cultural and linguistic differences must be understood and respected by medical providers. Both consumers and providers need to be aware of immigration laws and regulations in both countries and the impact that it can have on access to health care. A SPNS grant in the California/Mexico border region designed to address health disparities for PLWH has provided useful information on ways to improve health care delivery in the area, but more research is needed to reach all PLWH in the area and address the complex coordination issues that arise in a transnational border region.

Goals

- Develop improved systems to assess and respond to the migration of new HIV-infected individuals into California from other states and nations.
- Promote the continuity of care for the U.S./Mexico border population, including both the transborder population that lives and/or works in the border area and continually travels between both countries, and the migrant population moving through the border region and throughout California.
- Train medical and social service professionals in the unique challenges of working in the border area, especially in the dual cultural approaches to accessing health and social services. Ensure providers are culturally and linguistically competent to work with the border population.
- Increase the level of outreach and education for PLWH in the border region, including education about HIV, information on the services available, and linkages to primary medical care and other services.

- ❖ Continue researching the health care needs of immigrants and border residents, as well as how best to coordinate care with Mexican providers and authorities.

Case Management Services

Case management is available to PLWH throughout the state. Case management serves as a primary access point to HIV health care and services. The main gaps in case management are related to coordination, cultural and linguistic competency, specialized case management, and quality standards. No person should experience lesser health outcomes because they are unfamiliar with or do not know how to access or navigate the HIV health care system.

At times, there is a lack of coordination among case management agencies within a given region. This lack of coordination can result in contradictory or incomplete case management services. When a client must access needed services from different agencies, and each agency assigns a separate case manager; the result can be fragmented or over-coordinated services. Case management records are sometimes disorganized or poorly maintained, which can hamper the smooth transition of clients between services and systems, especially during interagency referrals.

Although case management is widely available for PLWH, it is not always culturally appropriate or accessible for all. Successful case management relies on a relationship of trust and respect between the social worker or case manager and the client. That trust and respect are easier to build if there is a common language and a shared understanding of the cultural context in which the client lives. PLWH who do not speak English need case management in their own language, and case management in other languages, including Spanish, Tagalog, Vietnamese, Cantonese, and Thai, remains a gap in many areas of the state.

Funding has been sporadic or inadequate for the specialized case management programs that support the intensive care and support needs of special populations such as youth or recently incarcerated individuals. While excellent examples of these programs exist in some regions, they are non-existent or underfunded in others. Nursing case management is particularly needed by PLWH with advanced HIV disease and other chronic health conditions. As the population of PLWH ages, nursing case management will become a greater need and a larger gap. Transitional case management for PLWH being released from correctional facilities is vital to linking people with services in the community, but is sporadic across the state, despite PLWH being released to all counties.

Statewide standards for case management or specialty case management have not been implemented in California, and several definitions of what constitutes case management exist. Some individuals need intensive case management, while others need little or none. Clear case management standards could help to define appropriate caseloads based on acuity. Excessive caseloads can lead to a lack of adequate attention to clients' needs and can delay access to needed services. Fluctuating

caseloads and inadequate staff training may also result in case management services of an uneven quality. More fluid case management models are needed to better respond to fluctuating client conditions and needs over time.

Goals

- Improve the quality of service access and coordination for PLWH by increasing the professionalism, relevance, comprehensiveness, and client sensitivity of case management services at all levels of care, and by expanding efforts to create and support integrated case management systems and definitions throughout California.
- Expand case manager training and education; ensure greater consistency in staffing; recruit greater numbers of self-disclosing HIV-positive and other peer case managers; increase bilingual case management capacity; reduce inflated client caseloads; and facilitate greater integration and consolidation of regional case management systems among social and medical service agencies.
- Seek a consensus definition of case management.
- Maximize the effectiveness of case management services throughout the state. Create better data systems to strengthen evaluation and improvement of case management. Support development of appropriate exit strategies from case management and greater self-reliance among clients.

Co-morbidities and STDs

Co-morbidities such as TB and hepatitis can complicate the treatment of HIV disease, and speed up the progression of disease in PLWH. STDs can also affect the transmission of HIV. Accurately diagnosing and treating co-morbid conditions is essential to ensure good health outcomes, and is a part of high quality medical care for PLWH. Liver diseases, and hepatitis C in particular, are increasingly common among IDUs, and can interfere with treatment for HIV, limiting the medications that can be used, and depriving people of treatment options. Hepatitis vaccines should be available to all PLWH for whom they are medically indicated.

Goals

- Establish HIV testing as a standard of care in all STD clinics, and treat these clinics as key points of entry into the overall HIV/AIDS care system. Ensure that screening, diagnosis, and treatment of STDs is part of the HIV standard of care, with referrals to prevention services when appropriate.
- Strengthen the existing service system to better respond to the escalating epidemic of hepatitis C—including improved education, prevention, testing, and treatment, and link this system more fully to the existing HIV care system. Ensure that hepatitis vaccination and treatment is part of the standard of care for HIV.

- ❖ Establish HIV counseling and testing as a standard of care for all persons with confirmed or suspected cases of TB in California as well as regular TB testing for at-risk PLWH.

Communities of Color Issues

Communities of color, including African Americans, Latinos, Asians/Pacific Islanders, and Native Americans, face major barriers to care. Issues of stigma, addressed in the section on cultural issues, are also very relevant to communities of color. California is a very diverse state, with refugees and immigrants from all over the world. In California, communities of color include African immigrants, Central American refugees, Hmong farmers, Native Americans on rancherias or in urban areas, Latinos, South Asians, and migrant workers. Each community has its own assets, strengths, and challenges that need to be considered. African Americans and Latinos are highly impacted by the epidemic in California, and their concerns are described in more detail below.

<u>African Americans</u>

African Americans face disparities in access to care and other services throughout the United States, including California. Studies have shown that African Americans face disparities in access to and quality of care for a number of health conditions. Neither California nor HIV is unique in this respect, unfortunately, and the larger health and social systems need to be reformed to eliminate the disparities still experienced by African Americans.

African Americans are disproportionately affected by HIV in California, carrying a burden of HIV disease many times larger than their presence in the population. In some parts of the state, African Americans are less likely to be on ARV therapy, more likely to be out of care, and have lower survival rates. Many African Americans share a cultural mistrust of the medical establishment, including clinical trials and medications, because of past experiences such as the notorious Tuskegee study.

The system of care for PLWH in California is working to identify and address disparities for people of color, including African Americans. There are community-based organizations providing excellent culturally sensitive care. More services, including outreach, education, and peer advocacy are needed to bring African Americans into care. OA has created an African American HIV/AIDS Initiative to develop policy, programmatic, and funding guidelines for the state, and the California Legislature passed a law in 2005 calling for that initiative to be expanded.

<u>Latinos</u>

Latinos in California face disparities in access to health insurance, health care, and other essentials. Latinos with HIV are also less likely to have health insurance, and, therefore, are more heavily reliant on CARE Act funding services than other groups. Monolingual Spanish speakers have linguistic barriers to care, as well as cultural

concerns. Latino immigrants in California come from all parts of South, Latin, and Central America and the Caribbean (which can have different cultures). Latinos who have been in the United States for generations have needs and concerns that may not overlap with those of more recent immigrants. Staying in medical care is even more of a challenge for migrant workers, especially those who travel between Mexico and the United States.

As described by El Proyecto Del Barrio, a Title III program in Los Angeles,

> "Stigma regarding HIV and AIDS continues…among Latinos. Many male Latinos who have sex with men do not identify as gay or bisexual. In several needs assessments conducted by the program, Latino MSM often comment that they are not comfortable seeking services in "gay identified locations" or AIDS-identified service organizations. Many persons with HIV in the service area are not open about their HIV status. Staff estimate that 75 percent of Latino clients are not open about their HIV status to their families… A large proportion of individuals living with HIV disease in the service area are indigent gay, bisexual or MSM. They are subject to the same structural barriers that have historically prevented other minority groups from receiving quality medical and social services. The Latino MSM/W community is isolated by culture, language and geographic barriers from mainstream gay community resources, receive little support from within the Latino community due to stigmas associated with AIDS and homosexuality, and lack a formal sense of community among themselves."[12]

See the issues listed under Stigma for additional goals relevant to communities of color. Stigma is certainly not limited to communities of color, but it is one of the major barriers faced by people of color living with HIV/AIDS.

Goals

- Ensure the availability of culturally appropriate, community-based services for all communities of color affected by HIV/AIDS in California, including African American, Latino, Asian/Pacific Islander and Native American populations. This includes expanding the number of people of color in direct care and service positions at all levels of care and service, and ensuring greater availability of care services directly within ethnic neighborhoods.
- Place a greater emphasis on expanding the availability and utilization of preventive care services by communities of color, who, because of economic, language, historical distrust of medical institutions, or residency issues, often utilize health care services only for critical or emergency care needs. Develop more health promotion services targeting communities of color. Support

[12] Title III Application, El Proyecto Del Barrio, 2004. p. 18.

programs that teach self-management and reduce dependency on social services.

- ❖ Examine the ways in which the existing system of HIV service and support will need to change or become more flexible to address those populations that are becoming more frequently affected by HIV. Ensure ongoing flexibility in the location and scheduling of care and services for these and other populations.
- ❖ Continue to address language, literacy, and cultural barriers to care for PLWH whose primary language is not English, particularly in terms of the severe lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific Islander languages, including Cantonese, Tagalog, Vietnamese, Cambodian, and Thai.
- ❖ Reduce barriers to HIV-related health care for Native Americans living both inside and outside of reservations, including expanding culturally competent care and support services in city-based facilities. Coordinate services wherever possible with care funded through the Indian Health Service of the Bureau of Indian Affairs.
- ❖ Continue to promote outreach to and collaboration with community of color-based organizations and faith-based groups by larger health care institutions and CARE Act-funded providers, particularly as they serve as key entry points for bringing persons of color living with HIV/AIDS into the overall continuum of care.

Complementary Therapies and Treatments

The HIV service community increasingly recognizes the value of alternative and complementary therapies such as acupuncture, herbs, and traditional Chinese medicine. Complementary therapies can help manage side-effects, support overall health and well-being, and provide pain management. Acupuncture is useful for treating addiction. Many PLWH choose to use complementary care in conjunction with Western medical care, and such care has been proven effective in many areas, including reducing the side effects of medication. However, some clients utilize non-Western sources of medicine without sharing this information with their primary care physician. Since complementary therapies can be potent, and may affect the efficacy of ARV therapy, it is important to educate clients and physicians about the need to discuss and coordinate care for people who choose to use complementary therapies.

Goals

- ❖ Ensure access to high-quality, affordable complementary therapies and treatments that reduce the side effects of HIV medications, promote wellness, and reduce stress. Examples of such therapies may include: acupuncture, acupressure, or herbal treatments, with selection of treatments based on local and state regulations, agency programs, and identified client needs.
- ❖ Educate both patients and providers about the need to coordinate Western and complementary care to avoid harmful interactions and maximize benefits.

Correctional Settings and Incarcerated Individuals

California has the third largest correctional system in the world.[13] In California, hundreds of PLWH are incarcerated at any one time. While some progress has been made, services for PLWH in correctional settings remain severely inadequate in many cases. State prisoners are one of the few groups have a constitutional right to medical care, although the quality and accessibility of that care is sometimes lacking. They need care that is equivalent to the services available within community settings, including referrals to specialists, pain management, diagnostic tests, medications adherence support, and ongoing education about treatment options. However, the California state prison health system is currently facing questions over its ability to provide that standard of care for all inmates, and may need to make significant changes in the next few years.

Physicians in correctional settings need training on HIV interventions and treatments. HIV risk-reduction materials, including condoms, should be widely available in correctional settings in order to prevent new or cross-infections. HIV status should not preclude access to mental health or substance abuse services, or to jobs or educational opportunities. While some providers believe that important steps to improve the quality of HIV/AIDS care in correctional settings have been taken, one consumer focus group participant said, "Nothing in the criminal justice system is HIV friendly."

As larger numbers of PLWH are being returned to the community due to jail and prison overcrowding, or transferred among different correctional settings, it is essential that transitional services and support for parolees be provided, including ensuring that prisoners are released or transferred with a supply of prescribed medications, and with appropriate linkages to or services. This support includes an intensive range of services that help prisoners find and maintain affordable housing, and have access to transportation and food. It also encompasses access to and retention in primary medical care and other care, including substance abuse treatment. Adequate substance abuse treatment is lacking, and many inmates with HIV/AIDS are released without appropriate links or referrals to care in their community. The increased care burden on community-based HIV/AIDS organizations due to recently released individuals also needs to be recognized and subsidized.

PLWH in state and local correctional facilities face gaps in care upon release from jail or prison. In particular, they are at risk of interruptions in their medications and health care. Collaboration between local clinics and the correctional staff is sometimes hampered by bureaucracy, regulations about release of information, lack of sensitivity to HIV, or over-burdened staff. Transitional case management by case managers with jail and prison clearance can ensure enrollment in ADAP upon release; access to short-term housing; and linkage to primary care, substance abuse treatment, mental health

[13] Center for Juvenile and Criminal Justice. http://www.cjcj.org/cpp/ccf_growth.php, accessed January 14, 2006.

services, and other programs in the community. Transitional case management programs can also reduce recidivism.

Consumers who have histories of recent incarceration or poor credit are frequently only able to obtain substandard housing. New processes are needed to facilitate the entry of people with HIV/AIDS who have incarceration or poor credit histories into new housing opportunities.

Goals

- Ensure that all incarcerated individuals have immediate access to appropriate medical care, including referrals to specialists, pain management, diagnostic tests, and accurate information about their treatment options. Develop systems to ensure better accountability and higher quality health care within the California prison system, and to bring the quality of HIV/AIDS care and service in correctional settings to the level of community-based standards of care, including PHS treatment guidelines.
- Ensure that PLWH are able to take their medications as required, in coordination with meal schedules as needed, and that prison policies do not interfere with the ability for PLWH to take their medications. Ensure coordination of HIV services among different incarceration settings, and ensure continuity of care following prisoner transfers.
- Ensure that PLWH receive appropriate services in local jails and juvenile detention facilities. Protect the confidentiality of incarcerated PLWH.
- Ensure the provision of transitional services with linkages to the community for PLWH being released from incarcerated settings. PLWH should always be released from prison with a supply of any prescribed medications, complete medical records, and linkages to all appropriate community services.
- Increase funding for transitional case management services for county and state correctional systems.
- Expand the participation of correctional and criminal justice experts on HIV planning bodies in California.

Dental and Oral Health Care Issues

The lack of oral health care services remains a significant gap in HIV services in California. Needs assessments from Title I areas ranging from Sacramento to Orange Counties identified dental care as a top unmet need for PLWH. There are only a handful of Part F Dental Reimbursement Programs in California, all located at dental schools, and many PLWH live outside the catchment area. Denti-Cal, the Medicaid dental coverage in California, has very limited coverage for adults. There is an overall need for affordable, quality dental and oral health care across the state. PLWH face a number of opportunistic infections that are often first diagnosed by dentists. PLWH face a number of oral health challenges including advanced periodontal disease and an exacerbated response to oral infections. Regular dental care can help ensure that

PLWH are able to eat and receive needed nutrition. Dental problems are more prevalent among substance users, particularly those using methamphetamine, leaving substance users with HIV with even greater needs for dental care.

Some dentists are still unwilling to treat people with HIV. Other issues that affect the accessibility of oral health care services include the lack of publicly funded dental benefits and the low reimbursement rates dentists receive as payment for those individuals who do have benefits. Private dental insurance policies that finance dental services under a reimbursement model in which patients must pay for dental services and then wait for reimbursement by an insurance company may limit access to expensive dental services for many patients.

- ❖ Ensure the full available of adequate and comprehensive oral health care services for PLWH across all regions and populations. Create a statewide mechanism for recruiting oral health dentistry fellows, and emphasize dentistry as a topic to be covered by AETC's provider training activities. Make new funds available to expand and create new dental and oral health services for PLWH through existing CARE Act titles.

Direct Emergency Financial Assistance (DEFA)

DEFA offers a vital lifeline for low-income PLWH facing financial crises or temporary income shortfalls. It provides episodic support to individuals for medical co-pays, utility bills, unexpected medical expenses, or rent. This assistance is particularly important at a time of rising energy and heating costs. Title I EMAs may also be able to use emergency financial assistance to offset the costs of the Medicare Part D drug benefit for PLWH otherwise facing increased costs for their medications. DEFA helps prevent homelessness and facilitates continuity of drug treatment therapy, helping improve the health and well-being of PLWH.

- ❖ Maintain the availability of direct emergency financial assistance services for low-income PLWH.

Employment Development, Placement, and Training Issues

Many PLWH are experiencing improved health as a result of combination therapies, and are now addressing issues with returning to work. With counseling, job training, and benefits counseling, more PLWH will be able to learn self-management skills, earn an income, and eventually no longer be reliant on case management and public benefits.

However, PLWH face several significant barriers, and have some critical needs, related to this decision. Many PLWH with insurance, for example, are concerned about losing health benefits if they resume employment, or of becoming ill and once again finding themselves unable to work. These consumers are in need of significant legal and benefits assistance, ideally through trained benefits counselors and/or through trained case managers, to help them make this transition.

PLWH need expanded work and volunteer opportunities which make allowances for fluctuating health and energy levels. Such employment programs would ideally be linked to existing opportunities through the various federal, state, and local agencies that focus on rehabilitation and employment development. Men and women with children also need access to subsidized child care services to allow them to return to a full- or part-time job. There is a serious need throughout the state for expanded vocational training and rehabilitation programs; for new employment placement and assistance programs within community-based agencies; and for programs to orient and train business owners and employers about the specific issues related to PLWH in the workforce.

- Support PLWH in their efforts to compete successfully for part-time, temporary, or full-time employment. Provide counseling, training, and other assistance needed to ensure job-related education, training, retraining, or trial work periods, applying federal guidelines if the individual is receiving disability benefits.
- Improve coordination among federal, state, and local government and private sector organizations that focus on habilitation, rehabilitation, and employment.

Families and Children

Families of PLWH are also affected by the disease. Perinatal transmission of HIV has fortunately dropped close to zero for California, although there are still hundreds of children living with HIV in the state. Children with one or more parents living with HIV face issues and concerns that their unaffected peers may not, yet few services are designed for them. They may have developmental issues and need additional counseling and support as they grow older.

Child care is a gap for women and families with children. Without respite child care, it can be difficult to attend medical appointments. High insurance costs and safety concerns for children sometimes hinder agencies from offering on-site child care that could be utilized while clients access services at that agency. This is not only an issue as a service category, but it is also a systemic barrier to accessing medical and social services. Despite the identification of child care as a gap and a barrier to care, many EMAs are unable to fund this service because of higher priority needs. Ongoing child care is a gap for many families as well.

See the section on Women for a more comprehensive description of the issues facing women with HIV/AIDS.

Goals

- Ensure children's access to comprehensive and coordinated, family-centered and developmentally appropriate HIV medical and support services.
- Ensure comprehensive developmental evaluations and interventions to promote learning, participation in school, and youth participation in medication adherence.

Improve family-focused assessment skills and develop treatment plans for families. Help families plan for the future through education about and improved access to permanency planning.

- ❖ Promote community planning efforts for multi-system interventions for families. Increase the capacity of agencies serving adults to assess family needs and facilitate care for children.
- ❖ Advocate with health care systems for supportive mental health and other psychosocial services for children affected by HIV, including HIV-negative children with HIV-positive parents.
- ❖ Increase resources for child care, both respite child care to enable access to medical and social service appointments for parents and other family members, and ongoing child care. Support CARE Act-funded agencies in offering on-site child care.

Food and Nutrition Services

Adequate food and nutrition services remain a critical and ongoing need for low-income PLWH in California. This need increases as the population of PLWH becomes increasingly impoverished and requires longer-term support and care. Ensuring access to high-quality foodstuffs, including high-calorie nutritional supplements, home-delivered meals, vitamins, and packaged and prepared foods, is essential for maintaining and prolonging the health status and life expectancy of PLWH. Nutritional counseling and education by registered dieticians can also help PLWH manage some medication side effects, get optimal benefit from their medications, and improve their health status. Food services such as community food banks need to take into account the cultural and ethnic food preferences of the people they serve. Many communities have resources for food for low-income members, but those resources are not always identified by and linked to by HIV services.

- ❖ Ensure continued access to food and nutritional services, including nutritional counseling, for PLWH. Help HIV service providers identify and link to existing community food resources.

HIV Testing, Case Reporting, and Confidentiality

Up to 27 percent of PLWH in California still do not know their HIV status, according to CDC estimates. These individuals need to be reached with HIV counseling and testing so they may learn their status and access health care. HIV testing is offered in a variety of venues and modalities, including both anonymous and confidential testing sites. HIV counseling and testing continues to expand and reach more individuals at risk of HIV infection, especially as rapid HIV testing is rolled out across the state.

California HIV counseling and testing programs are designed to link newly positive people into care. Linkage to care is a top priority for test counselors, and requires a strong connection to the HIV care and treatment system. California has developed

CDAPS to help PLWH disclose their status to sexual and needle-sharing partners, which can be an important resource for newly diagnosed PLWH.

California is poised to transition from a non-name based HIV reporting system to a name-based reporting system. Legislation to allow HIV reporting by name was introduced in January 2006, and has broad community support. Concerns about confidentiality remain a barrier to testing for many, and any HIV testing and surveillance system must address those fears. State legislation currently expands penalties for any unauthorized disclosure of someone's HIV status. There has never been a breach of confidentiality in OA's surveillance systems.

Fears related to confidentiality can become a barrier to care when individuals are worried that their HIV status will be disclosed if they seek testing or care. These concerns persist for some individuals despite the fact that the law strictly prohibits disclosure of an individual's HIV status without their explicit consent in most settings. Confidentiality issues can also be problematic when individuals fear that their personal behaviors, decisions, or life choices will be exposed, criticized, or stigmatized.

Goals

- Continue to improve links from HIV counseling and testing programs to HIV care and treatment services, and make referrals and linkages as seamless as possible for newly positive PLWH.
- Encourage PLWH to access CDAPS if they want help with partner counseling and referral services.
- Continue to protect the confidentiality of all PLWH in California, particularly as reporting requirements related to HIV change.
- Provide training and resources to local health jurisdictions to implement any new laws or regulations related to HIV reporting, HIV testing, and linkages to care.

Home Health Care and Day Health Care

Home health care services are a vital link in the continuum of HIV/AIDS care, providing homebound persons living with advanced HIV disease access to high-quality personal care and monitoring, while helping maintain dignity and independence in the face of a debilitating, life-threatening illness. Adult day health care services can help people remain in their homes for longer by providing day services including nursing care in an outpatient setting. It also supports adherence to medications.

In some California regions, reduced HIV funding has led to the reduction or elimination of home-based services for PLWH, including home health, attendant, and nursing care; hospice care; and respite care for family members and other caregivers. The only licensed adult day health care program for PLWH in California recently closed because of funding cuts. Neither Medi-Cal nor Medicare covers the full array of home health and hospice services needed. Because of the special needs of many AIDS-diagnosed populations, including multiple diagnoses, dementia, and other factors, it is often difficult

to identify providers for these services from other non-HIV-specific agencies and programs.

The demand for hospice services has significantly decreased since the introduction of ARV therapy. However, residential and daycare for those with AIDS-related dementia continue to be services that many communities are not able to provide. As PLWH age, there will be increasing needs for HIV-competent senior services, whether that means senior programs welcoming PLWH, or HIV agencies acquiring geriatric expertise.

- ❖ Ensure continued access to home health and hospice care for PLWH, including long-term care, access to RCFCIs, and specialized dementia care programs.
- ❖ Expand the availability of day and respite care services throughout California, and increase the availability of licensed adult day health care facilities, particularly in rural areas. Ensure that existing day and respite capacity is not lost.

Housing and Homelessness

The housing crisis in California continues to create a major gap in care for PLWH. Housing is a bottleneck service: if PLWH do not have housing, it is more difficult for them to access all other services and to get the full benefit from medical care and medication. There is a lack of affordable, safe housing units for all low-income groups in California. The number of low-income households in need of rental units in California's metropolitan areas in 2001 exceeded the number of available low-cost housing units by more than two to one, a gap of 650,000 units. Housing in California continues to rise out of reach of most of the state residents. The 2005 *Paycheck to Paycheck* report by the Center for Housing Policy found that **all** of the top ten least affordable cities were in California. That was true both for renters and for homeowners.[14] Even in communities that have effective housing programs for people with HIV, these programs are frequently inadequate or inappropriate for certain populations such as large families with children. There is a shortage of approaches to help people with HIV overcome hurdles to obtaining long-term housing such as a poor credit record and a lack of residency history.

> PLWH who are under severe economic stress must prioritize pursuit of basic living needs over seeking and maintaining health care. If a homeless PLWH who is not severely ill must choose between finding a meal and keeping a doctor's appointment or going for a blood-draw, she is likely to choose the former. Transportation is also a major barrier, if the clinic is not within walking distance and the individual does not have bus fare, he is not able to attend the clinic. Homeless people lack telephones to make appointments and refrigerators to store medications. As a consequence the homeless/disadvantaged person is less adherent, becomes sicker when she does get sick and requires more advanced medical and supportive services to weather the crisis. All of these factors add to cost and complexity of care.
>
> - Oakland EMA 2005 Title I Application.

[14] 2005 *Paycheck to Paycheck: Wages and the Cost of Housing in America*. Center for Housing Policy, National Housing Conference. August 2005.

Housing programs in rural regions are undersupported in general. Needs assessments routinely find housing is a top unmet need for PLWH.

Housing Opportunities for People with AIDS (HOPWA) is a separate federal funding stream through HUD. It helps fill the gap in housing assistance for PLWH in California, but is not sufficient and has faced cuts of its own in recent years. Because there is a separate funding stream for PLWH, other housing programs are often not set up to work with PLWH, or assume that their needs are met elsewhere.

The housing crisis in California has a disproportionate impact on those who are poor, homeless, or marginally housed. Providing health care and other services to the homeless and marginally housed is more complex and more costly, they often need to stay in expensive inpatient beds for longer periods awaiting community placements, are more likely to miss appointments, and are more likely to access care through the emergency room. Stabilizing the homeless is essential to providing them with optimal care. It is particularly difficult for homeless PLWH to access ARVs without a secure place to store medications and recuperate from side effects such as diarrhea and nausea. Lack of housing is one of the most significant barriers to care in several EMA needs assessments.

Goals

- Ensure that PLWH, including families affected by HIV, are able to access a comprehensive continuum of housing services and resources, including emergency shelter, transitional housing, housing/rental subsidies, foster homes, congregate living facilities, skilled nursing facilities, board and care facilities, transitional housing for parolees and others released from prisons and detention facilities, clean and sober living environments, and housing for people with multiple diagnoses. Ensure that HIV/AIDS housing is available in the least restrictive form desired by each individual.
- Develop strategies and technical assistance resources to help communities' access additional housing resources for PLWH. Encourage and provide incentives for local jurisdictions to utilize HUD funding, and other housing funds as sources for building or converting low-income housing specifically for PLWH. Expand integration with Healthcare for the Homeless grantees and with local housing authorities.
- Ensure that care services are reaching the homeless, including those not in shelters or emergency housing. These men and women can be among the most difficult people with HIV/AIDS to reach, which means that additional efforts must be made in order to bring services to them, and to ensure that medical and other programs are fully accessible. Outreach and peer advocacy are essential components in this effort.
- Prevent homelessness and interrupted primary medical care through providing long- and short-term housing and outreach to those PLWH who drop in and out of care. Stabilize and maintain in care those most likely to be lost to care.

Immigration and Migration

Immigrants, especially those who are undocumented, experience significant barriers to accessing care. Recent immigrants from Mexico, as well as Central and South America are likely to be monolingual Spanish speakers, and many are not literate in any language. Immigrants from Asia and the Pacific Islands may speak any of over 100 languages and dialects. Language can be a barrier to care if a provider is unable to clearly communicate with their patient about symptoms, medication requirements, and side effects. Undocumented immigrants may be reluctant to access services for fear of being deported for being HIV positive, or fear that accessing services may result in being found a "public charge." Undocumented individuals are ineligible for Medi-Cal, leading to much higher uninsured rates among immigrants, and a greater reliance on CARE Act-funded services.

Many immigrant populations may choose not to seek HIV services because they fear that providers will report them as undocumented, potentially resulting in deportation. Others do not seek services because of the mistaken but understandable assumption that publicly funded HIV care services cannot be accessed if an individual is not a documented immigrant or citizen.

Migration can affect the quality of HIV service provision in at least three ways, all of which affect the continuity of care services. These include:

- migration from other states into California;
- migration within California, such as between urban and rural areas, or between multiple rural regions in the case of migrant farm workers; and
- migration between the United States and Mexico.

As PLWH move across systems of care both within and outside of specific regions, service access can be hindered if there is a lack of coordination between HIV and non-HIV agencies, both public and private. Limited coordination among community-based, county, and state agencies in regard to planning, information sharing, and service delivery can also create disparities, as can inadequate coordination among local HIV service organizations.

The movement of people with HIV between states and regions can also cause disparities. CARE Act funding allocations are based on case reporting that identifies the number of people who received an initial HIV/AIDS diagnosis in a given region, rather than on the number of people actually living with HIV/AIDS and using services in a given region. Movement between California and Mexico is even more problematic because of the comparative lack of HIV care in Mexico. See the section on Border Health for more details.

❖ Ensure that comprehensive and culturally appropriate HIV/AIDS care and services are provided to all immigrant and undocumented persons in California regardless of

their residency or migration status. Ensure that immigrants with HIV are educated about their ability to access health care and other services.

- ❖ Develop improved systems to better assess and respond to the extensive and continual migration that occurs within different regions of California, including between urban and rural areas, and within migrant worker communities.

Legal Services

Legal services are invaluable to PLWH. End-of-life issues such as wills, trusts, plans for family members and dependent children, and health care powers of attorney are some of the needs that are best addressed by legal professionals. Unfortunately, PLWH continue to face illegal discrimination and denial of benefits.

- ❖ Ensure that PLWH have full access to legal support and assistance services, including support with accessing benefits and insurance, combating and overcoming discrimination, wills and end-of-life issues, permanency planning for family members, immigration, and understanding their rights as employees.

The Aging HIV-Affected Populations

In large part because California was one of the earliest epicenters of the epidemic, it is now home to increasing numbers of long-term survivors who are growing older and have to address health challenges related to aging as well as HIV disease. This group will likely increase over time, as already-infected PLWH grow older. People over 50 are also becoming newly infected with HIV, adding to the numbers of older individuals with HIV/AIDS.

The San Francisco needs assessment identified the population of PLWH over 55 as a priority population for the first time in 2005. Sacramento also reports that:

> "As patients age they require more care for conditions associated with aging including diabetes, heart disease, chronic obstructive pulmonary disease (COPD) and high blood pressure. The diseases of aging interact with HIV disease to make care more complicated and costly. For example, many antiretroviral medications cause elevations in blood lipids which can worsen arterial disease process than may be already underway. The EMA's sole HIV primary care clinic's (CARES) physicians report that they are seeing middle aged AIDS patients whose HIV disease has stabilized, but who are seeing the doctor primarily for conditions associated with advancing age. Such patients require more frequent visits, therefore, placing an increased burden on the system."[15]

[15] Sacramento EMA 2005 Title I Application, p. 45.

As PLWH age, they need a distinct set of services, including long-term housing, basic job training, vocational rehabilitation, job placement, client education, insurance assistance, benefits advocacy, policy research, financial planning, and secondary prevention support, which is oriented toward helping them live longer, more productive, and more self-sufficient lives.

Goals

- Examine the ways in which the HIV service system will need to evolve to confront the fact that many men and women with HIV and AIDS are living longer and growing older. Address the fact that the growing perception of HIV disease as a chronic, non-life threatening illness is affecting both the availability of resources and the ability to sustain existing systems of care.
- Ensure that as PLWA continue to live longer, healthier lives, that adequate medical attention and resources are focused on the new health problems beginning to emerge among these populations, including diabetes, lipodystrophy, heart disease, liver disease, manifestations of hepatitis C, and preventive and restorative dental care. This includes health, psychological, and social impacts of aging as a person with HIV, including issues of isolation and lack of social interaction. Provide expanded cross-training, education, and enhanced resources, and more information on medication interactions and metabolic complications. Ensure that care and treatment resources continue to be available at a level commensurate with the growth in the overall population of PLWH to be served.
- As aging populations create greater needs for preventive health services for PLWH, including an expanded emphasis on cardiovascular health, regular procedures such as breast and prostate exams, and ongoing patient health education in regard to self-care and non-HIV health needs. Provide greater levels of specialty care to meet increasingly complex patient needs.
- Expand the availability of residential-based services for PLWH who are very ill and who need the support of residential settings in order to start on ARV therapies with the hope of recovery. Expand opportunities for persons living longer with HIV/AIDS to participate in community activities, including more chances to socialize with others with HIV/AIDS, and more options to volunteer.

Managed Care and Medicaid

Medicaid in California is called Medi-Cal. Some PLWH on Medi-Cal are already enrolled in Medi-Cal managed care. Proposed Medi-Cal reforms in California call for enrolling more disabled people, including PLWH, in managed care systems as a cost-saving measure. Many PLWH are also in private managed care programs, including Medicare managed care. Managed care programs in the past have not always been able to provide PLWH with trained specialists or the highest quality care. Now, however, managed care programs in California, including those funded by Medi-Cal, are required to provide PLWH access to HIV specialists, although they are sometimes not geographically accessible.

Goals

- Ensure that PLWH who are enrolled in managed care systems have access to the leading standards of care for HIV disease, and that the quality of care they provide is at least equivalent to community-based standards of care outside of managed care settings. Ensure that managed care organizations provide geographically accessible and experienced HIV/AIDS service providers for all PLWH, and that existing regulations are enforced. Require that a clearly understood and easily accessible consumer grievance system be in place within all managed care programs.
- Adjust managed care capitation rates or create "carve-outs" where needed to reflect the full range and frequency of higher costs of service provision for PLWH. Ensure an adequate Medi-Cal capitation rate that includes drug treatment, outpatient medical and dental care, social services, and the risk of extreme inpatient care costs.
- Ensure continuation of Medi-Cal benefits for persons with HIV disease, and expand Medi-Cal in California to cover not only persons living with AIDS, but also PLWH who meet income criteria. Encourage the State of California to move forward with waiver requests and supportive legislation as both a humane and cost-effective approach to financing HIV/AIDS care.
- Ensure and enhance coordination between Medi-Cal and CARE Act systems, and between Medi-Cal and other systems of community care throughout California.

MSM

The category of MSM includes men who identify as gay or bisexual, and those who do not identify as such. MSM continue to be the vast majority of PLWH in California, as they have been since the very beginning of the epidemic. They have the highest prevalence rates of any group in California, and are living with HIV at rates truly disproportionate to their presence in the population. There are MSM in every city, town, and county of the state, every economic class, and in every racial and ethnic group. Their needs vary, based on their identity, context, and behavior. Stigma and homophobia remain barriers to care for many MSM, especially those in rural areas, those in communities of color, and those who do not identify as gay or bisexual.

The large populations of gay and bisexual men with HIV/AIDS in the state require services that consider, acknowledge, and accept behavioral differences. Services that dismantle social barriers and stigmas surrounding sexual orientation are vital to ensure access to services. In addition, there is a growing need for culturally and linguistically competent services, with qualified bilingual staff. CHPG recently developed the *Framework for Gay Men's Health and Wellness*, which describes an asset-based approach to health care and prevention for gay men that focuses on larger community health issues than just HIV, and states that a too-narrow focus on HIV may need to be

replaced by a broader agenda to deliver effective health promotion and disease prevention services.[16]

- Implement the *Framework for Gay Men's Health and Wellness*, as developed by CHPG.
- Address homophobia and stigma as a barrier to care for MSM. Ensure that culturally appropriate services for gay/bisexual men are accessible and available across the state.

Mental Health and Counseling Issues

Mental health services are one of the most widely used CARE Act-funded services. PLWH need mental health services ranging from peer support groups to crisis counseling to ongoing psychiatric care with medication. There is a shortage of long-term counseling and therapeutic services and psychiatric care for PLWH. Mental health services can be beneficial in improving self-care, promoting HIV medication adherence, and reducing HIV risk behaviors. Some care providers lack the training and expertise necessary to understand and appropriately respond to some of their clients' mental illness-related behaviors. Mental health services must be culturally appropriate, as cultures have different understandings and expectations of mental health services. Increased availability of and access to psychiatric consultation is essential in providing effective care and support to mentally ill PLWH.

Mental disorders, whether chronic and severe or relatively minor, are pivotal factors underlying many people's inability to enter care, remain in care, or begin and maintain combination drug therapies. Among HIV-positive persons, the prevalence of mood and anxiety disorders and substance use disorders is significantly higher than in the general population. Stress, depression, and anxiety make it difficult for an HIV-infected person to cope with life in general, much less with the demands of an HIV diagnosis. More serious mental disorders contribute to stigma and disenfranchisement, and compromise individuals' ability to successfully engage in care. The poor judgment, difficulty forming relationships, and impulsivity associated with personality disorders can contribute to the inability to remain in care and to access vital support systems.

Persons with HIV infection may be contending with chronic mental and/or addiction disorders that were present before the onset of HIV infection. Others may develop transient symptoms of mental disorder as a response to their HIV diagnosis. These symptoms may actually be a reasonable response to the shock and stress of the diagnosis and may need no intervention other than supportive counseling. Conversely, these symptoms may represent the onset of more serious disorders that will require more intensive monitoring and intervention. Some HIV-infected persons may also develop serious symptoms related to HIV medications, (e.g., psychotic symptoms resulting from steroid-based medications) or related to the HIV infection itself.

[16] Gay Men/MSM Task Force, California HIV Planning Group, *A Framework for Gay Men's Health and Wellness*. 2005.

Staff at some health facilities may be uncomfortable dealing with mental health issues or may lack the needed expertise to offer appropriate care. This raises the issue of discrimination against the mentally ill as a barrier to care, not necessarily through conscious rejection of mentally ill people by the medical care system, but through a lack of resources, knowledge, or skills to provide adequate care.

- ❖ Ensure that PLWH are able to access appropriate mental health assessments and treatment programs, including psychiatric consultation and psychotropic medications. Ensure that such services make use of existing mental health service systems, and that they include patient psychiatric care, community-based outpatient treatment in individual and group modalities, short- and long-term therapy, support groups, crisis services, and residential treatment, in accessible and culturally appropriate modalities.

Multiply-Diagnosed Populations

In addition to the PLWH struggling with mental illness or addiction there is a group of PLWH who are challenged by both problems, often referred to as multiply diagnosed. They need the mental health services described above as well as the substance abuse treatment delineated in the Substance Abuse section. Each condition can exacerbate, complicate, or even mask the symptoms of the other condition. Individuals may use drugs and alcohol to manage their mental health problems, or may develop mental health symptoms as a result of ongoing drug use. Treatment programs for one disease often are unprepared or uninterested in treating the other as well, and there is a lack of programs for the multiply diagnosed in California. A comprehensive system for addressing the needs of multiply-diagnosed populations in California, individuals affected by HIV, mental illness, substance addiction, and homelessness and other co-morbidities, needs to be developed and implemented.

Goals

- ❖ Assure that the complex needs of these individuals are addressed so that they do not slip through the cracks as health systems focus more closely on cost efficiency and cost savings in light of managed care. Explore the possibility of integrated funding to support these services within a unified framework.
- ❖ Support the development of integrated and interdisciplinary models of care to ensure greater coordination among primary care providers, specialty providers, and case management and psychosocial services professionals. Increase the resources available to fund successful, effective integrated programs.
- ❖ Train providers in multi-disciplinary approaches to reaching and serving the multiply diagnosed. Increase cross-training opportunities for both mental health and substance abuse treatment professionals.

Peer Advocacy, Empowerment, and Self-Help Services

PLWH have a valuable role to play as providers, planners, and advocates in the system of care. PLWH are often their own best advocate, and can take the lead in improving their own health and quality of life. They are an essential part of the CARE Act planning process at the local and state level, although some PLWH need support, training, and mentoring to be active participants in the process.

There are too few PLWH working in both paid and volunteer positions in the care system in California who can provide direct assistance, support, and advocacy to others living with HIV. Some PLWH who are able to work choose to work in HIV care, others have been working in AIDS care since the beginning of the epidemic. Peer advocacy is one way that PLWH can be of direct service to others. These services can help overcome the isolation and loneliness that often affects client health, while serving as a vital link to services and socialization.

Many consumers believe there is an underestimation of the potential benefits of self-help programs for improving the quality of care for PLWH. This failure to recognize self-help programs can result in people with HIV not having consistent access to support and advocacy from other HIV-infected individuals. Some local or regional planning bodies do not provide options for funding clearly defined self-help programs, or fail to encourage the development of such programs. There is a lack of research evaluating the benefits that may accrue from people with HIV receiving services through self-help programs and agencies.

Goals

- Develop and implement programs that end social isolation among PLWH, and that empower PLWH to take greater a greater role in influencing and controlling the quality of their lives and health care.
- Ensure the continued availability of peer advocacy services through which trained individuals provide direct service, support, and assistance to PLWH from comparable or compatible sociodemographic backgrounds. Provide support and supervision for peer advocates to help them manage their role as a service provider.
- Ensure the participation of members of specific population groups, such as gay/bisexual men, women, young people, and people of color, in the development of services geared to those populations.
- Provide PLWH with the skills necessary to effectively contribute to local and regional planning and implementation processes, including making leadership training and technical assistance available on an ongoing basis.

Poverty as a Public Health Issue

Poverty has a significant impact on many PLWH. It is one of the most basic barriers to care, quality of life, and good health outcomes. People living in poverty must not only

face the burden of having insufficient resources for basic necessities, but they are often the individuals who are least likely to be familiar with the health care system, have the most distrust of traditional health care services, and are most in need of support in order to access basic medical care. Poverty is a consuming condition that often draws focus and attention away from health preservation and life improvement. Poverty creates barriers to accessing services, and creates additional needs for so-called "survival services" such as food and housing. Poverty is an independent predictor of worse health outcomes in multiple health studies.

- ❖ Address the fact that a growing percentage of HIV-related client needs and problems are rooted in poverty by developing effective methods to jointly address poverty and HIV issues in California. Increase opportunities to form and develop partnerships between HIV providers and poverty-related community groups and advocates in order to expand and deliver services for both populations.

Prevention with HIV-Positive Persons

Prevention with HIV-positive individuals focuses on supporting their attempts to maintain safe behaviors and avoid transmitting HIV to their sex or drug using partners. While the central role of HIV prevention services with HIV-positive people is now widely recognized, published research about successful model programs is still limited. As more information becomes available about appropriate and effective transmission prevention services with HIV-positive people, including services provided directly by PLWH, it is essential that this information be made available. Lack of dissemination and effective implementation may result in inadequate, ineffective, or hastily constructed programs.

Creating and sustaining behavior change is difficult and requires approaches that are highly individualized and that take culture and context into account. Providers and funders must recognize that HIV prevention often requires long-term interventions and support and is rarely adequately addressed via basic prevention messages and traditional HIV education. The lack of individualized, long-term support may limit the effectiveness of HIV prevention with HIV-positive persons.

Some prevention with positives programs could be enhanced by providing training and support for staff and volunteers, especially as needed to counter unrealistic expectations they may have for their own and their clients' success. Unreasonable expectations for behavior change can contribute to client anxiety and create an environment in which it is difficult for clients to disclose the challenges they face in trying to achieve lower risk behaviors.

Goals

- ❖ Continue to develop effective and comprehensive prevention services for PLWH. Ensure that such services are focused on empowering persons with HIV to protect themselves and others; that they are provided in culturally appropriate,

respectful ways that take into account the emotional and mental health aspects of HIV/AIDS; and that they are coordinated with systems of care for PLWH.

- ❖ Ensure that prevention messages and interventions are tailored to PLWH as distinct and separate from prevention messages and interventions for negative individuals, and that they are nonetheless continually integrated and coordinated with HIV prevention efforts for HIV-negative individuals.
- ❖ Support disclosure assistance programs such as CDAPS designed to support PLWH in disclosing their status to sex and drug using partners.

Research and Clinical Trials

Clinical trials provide important opportunities for people with HIV to access new medications and treatment regimens. However, not all medical providers are aware of, or can advocate for, their clients' involvement in these trials, and, for many PLWH who live in rural areas, clinical trials may not be available. Clinical trials are sometimes not available to women of childbearing age because of the risk of complications to pregnancy due to antiretroviral toxicity. In response to pressure from the HIV community, many HIV drug manufacturers are taking extra steps to include diverse populations in their clinical trials programs. Community involvement in research can help address some of those issues, and can also help ensure that research findings are disseminated widely, especially for research into effective service delivery models.

Goals

- ❖ Include the broadest possible cross-section of populations affected by HIV/AIDS, including populations of color, adolescents and young adults, women, and IDUs, in government-sponsored clinical trials programs, and expand the opportunities for PLWH from all economic, geographic, and cultural backgrounds to participate in clinical trials research. Support research on complementary and alternative therapies as an important strategy for exploring potentially promising new treatments for HIV disease.
- ❖ Continue to expand support for research into models of service delivery, models of evaluating effectiveness and efficiency in care delivery; ensuring greater client adherence to care appointments and therapeutic regimens; service effectiveness; best practices; and the importance of cultural responsiveness in improving client adherence. Increase opportunities for collaborative interaction between researchers and providers at all levels of care. This includes broadening channels for disseminating and sharing research findings at the community level, and for finding ways to better incorporate research findings into community-based planning and program development. Support participation by HIV service providers in community-based research.
- ❖ Ensure that new advances in HIV-related treatment and care are quickly and continually incorporated into the care received by PLWH at the local level. Provide training opportunities for clinicians on the latest research results and how to incorporate them into clinical practice.

Rural Service Issues

PLWH in rural and frontier areas of the state face many challenges and disparities, including transportation, stigma, confidentiality concerns, lack of providers or specialists, and fewer services. They stress the ongoing difficulty of forming and providing a full continuum of care to HIV-affected men and women in isolated rural communities. These problems relate to both the dearth of qualified providers in rural areas, and to the great distances consumers must travel in order access individual services. Some communities have developed relationships with HIV specialty physicians from urban areas who spend a designated period of time once or twice a month in rural clinics, seeing patients on an appointment-only basis. However, the clinics often lack state-of-the-art instruments and testing equipment to allow adequate on-site diagnosis and treatment. Referrals to medical specialists to deal with specific health and medical problems are difficult. Even when services are available in rural areas, they are simply not accessible to consumers who are too sick to travel to these service sites, or who lack transportation options and subsidies to consistently keep appointments.

Sonoma County in California reports that it:

> "has experienced a steady drain of medical specialists due to the high cost of living, closure of several medical provider groups and the low Medi-Cal reimbursement rate, which was based on a rural standard. In consequence, patients must either be referred to providers in the San Francisco Bay area (more than an hour's drive one way, or an all-day bus trip) or be treated by their primary care physician. Local HIV clinicians are consequently performing many specialty procedures that would usually be referred to outside specialists. Gastro-intestinal issues, urology, neurology endocrinology, rheumatology and ear, nose and throat are just some of the specialty areas that must now be addressed at HIV clinics. For example, due to the lack of local gastroenterologists, primary care physicians at the HIV Clinic do treatment for hepatitis C. Higher syphilis rates complicate care and generate more office visits, tests, procedures and follow-up, as well additional visits for health education and hospitalization. This substantially increases the number of patient visits, procedures and health education sessions required."[17]

PLWH have identified the need for more sensitive and understanding rural physicians, particularly when dealing with communities of color and with gay and bisexual men. Many of these individuals wish their HIV status to remain confidential because of the stigma and hostility they face, and are mistrustful of the medical community's commitment to maintaining this confidentiality. Many gay and bisexual men living with HIV indicated that they feel they must remain closeted in rural areas, because of a lack

[17] Sonoma County EMA Title I Application, 2005. p. 39.

of support, and were afraid of having their sexuality exposed by medical providers and clinics.

- ❖ Address continuing HIV/AIDS service deficiencies and barriers in rural areas, including an overall lack of public health infrastructure, lack of transportation, housing, mental health, substance abuse treatment, or other support services or skilled service providers. Remedy the shortage of doctors, nurses, and other health care professionals qualified and trained in HIV care and other specialty care areas. Address stigma and confidentiality concerns as barriers to care in rural areas.

Stigma and Other Cultural Issues

Stigma is a social phenomenon that can hamper appropriate responses to an issue by complicating it with negative associations, judgments, and prejudices. HIV/AIDS stigma includes negative social attitudes toward AIDS as a potentially fatal illness and toward the behaviors that are associated with HIV transmission or groups of people who are identified with AIDS. These attitudes can lead to an unwillingness to discuss or deal with the issues or to denial of the reality of HIV and the urgency of the epidemic. Stigma directed at PLWH results in shaming and blaming feelings or attitudes toward people infected with HIV. These attitudes often inhibit persons with HIV from taking any action related to their HIV infection, including seeking medical care. Their resulting isolation and fear may not only affect their willingness to seek services, but also may affect their ability to disclose HIV status to families, friends, and even prospective partners. In HIV service settings, attitudes resulting from stigma can sometimes result in inadequate or insensitive service delivery, or to the marginalization of HIV-infected populations within the larger health and social service systems.

Gay and MSM of color often face more stigma related to both their sexual behavior and HIV. They are less likely to access care, and the Los Angeles Needs Assessment found that the most common barriers to care for MSM of color were a lack of knowledge, provider insensitivity, and discrimination.[18] Orange County reports that, "One challenge of serving this population is to reduce stigma associated with HIV. The EMA must enhance existing and develop new, innovative outreach strategies to bring non-White MSM into care. Stigma continues to inhibit treatment access in all non-White MSM populations."[19]

- ❖ Continue to reduce service disparities by ensuring that HIV care providers relate to and understand the particular life choices, needs, and cultural backgrounds of their HIV affected patients, and that they reflect, to the extent possible, the cultural, linguistic, and lifestyle backgrounds of the clients they serve.

[18] Los Angeles EMA Title I Application, 2005, p. 37.

[19] Orange County EMA Title I Application, 2005, p. 51.

- Address stigma as a barrier to care through education and social marketing campaigns and supporting community institutions such as churches to address HIV/AIDS appropriately in their community.

Substance Use and Addiction Treatment Services

IDUs and other substance users face high HIV risks, difficulties getting into care, and a higher incidence of co-morbidities such as mental health problems and hepatitis C infection, as well as other health problems related to substance use. They are far more likely than other PLWH to have a history of incarceration, homelessness, and to have been victims of violence and abuse, including domestic violence. For some IDUs, substance use is a barrier to maintaining regular primary care and adherence to medication schedules. Substance users have higher needs for basic survival services such as housing and food. Medical care and other services for substance users must be provided with a harm reduction modality to successfully retain them in care. Syringe exchange programs need to be available to IDUs to enable them to take care of their health and avoid contributing to new HIV infections.

The Los Angeles Title I Application described the issue:

> "Decreases in quality of life, income, emotional support, which usually accompany substance abuse, often result in or exacerbate isolation, mental illness, and increased risk for disease. Critical to effective services are HIV medical providers dually skilled at substance use and misuse issues. Case managers, housing providers and mental health providers require ongoing training to identify and respond to the potential for non-injection drug use and available treatment options. Additionally, all personnel working with HIV-positive individuals must be aware of issues related to increased high-risk behaviors that put clients in greater danger of transmission and re-infection. Training and education about substance abuse among the HIV-positive population is needed on a regular basis. Similarly, education from individuals' familiar with the lifestyle, such as peer counselors, is often shown to be more effective."[20]

Despite some progress, the goal of "drug treatment on demand" for PLWH remains unrealized. Extensive work remains to be done to ensure adequate access to drug treatment services for PLWH, a problem that is not unique to the HIV care system. Drug treatment capacity is inadequate, and appropriate and effective treatment modalities are not always available. Effective treatment for methamphetamine abuse is a major gap across the state. New treatment technologies and policies such as buprenorphine or office-based methadone treatment are underutilized and can help expand treatment capacity and offer more treatment options to PLWH. Simultaneously, legal constraints have limited the number of syringe exchange programs that are sanctioned and funded through public dollars.

[20] Los Angeles EMA Title I Application, 2005. p. 39.

There are wait lists for substance abuse treatment programs in every corner of California. That is true regardless of the community, region, drug of choice, or treatment modality. In some cases, there is no treatment locally available, such as residential treatment for women with children, or programs for monolingual Spanish speakers. Opiate addiction remains a major problem among IDUs in California, yet wait lists continue for methadone replacement programs, a well-researched, effective treatment option.

Methamphetamine and amphetamine use is a long-standing problem in California, especially for gay/bisexual men. It is now getting increased attention throughout the country, particularly from law enforcement. Successful methamphetamine treatment is a fairly new development, and there is little clinical research on what comprises effective treatment. Programs in San Francisco and Los Angeles report good outcomes, but also report that successful treatment for stimulant abuse may take longer than that for opiate or alcohol abuse. PLWH who want treatment for their methamphetamine addiction face significant gaps in treatment availability. Like all substance abuse treatment programs, methamphetamine treatment must be culturally appropriate to be successful.

The lack of sanctioned syringe exchange programs decreases the ability of providers to offer this valuable harm reduction service. Syringe exchange has been demonstrated as an effective means for reducing transmission of blood-borne pathogens including hepatitis C and HIV, yet syringe exchange programs are not funded or sanctioned in most counties. Legal barriers continue to limit resources for syringe exchange. Recent legislation signed into law by Governor Arnold Schwarzenegger has increased access to sterile syringes through pharmacy sales and through elimination of stringent requirements for establishment of local syringe exchange programs. This statute provides some legal access to clean needles and syringes and is a significant step forward in California's HIV prevention efforts.

- Increase the availability of harm reduction services at all levels, particularly needle exchange programs through which IDUs have access to clean needles every time they use drugs. Fully incorporate harm reduction services into other HIV/AIDS service and care modalities, so that consumers are not unnecessarily lost to the system, and ensure a high quality of harm reduction services.
- Educate and support active substance users in adhering to complex HIV treatment regimens regardless of their current drug use profile, and ensure that they are provided with access to medical care, social services, and comprehensive treatment alternatives at all levels.
- Increase funding for all levels of substance abuse and addiction treatment. Eliminate wait lists for treatment. Ensure the availability of culturally competent substance abuse assessment and treatment programs for all PLWH who wish to receive them, through a continuum of treatment options including residential (medical) and non-residential detoxification, short- and long-term residential care, and outpatient services.

- Ensure the availability of supportive services that help individuals achieve success in substance abuse, including transitional and supportive housing for individuals leaving treatment, transportation, mental health services, and job training and placement. Expand substance abuse–related service integration and coordination among providers, as well as development of expanded transitional "after-care" programs for HIV-infected and at-risk men and women in substance abuse treatment.
- Support the development, evaluation, expansion, and dissemination of effective treatment for methamphetamine and other stimulant addictions. Disseminate best practices from culturally-specific programs such as The Stonewall Project in San Francisco serving gay/bisexual men.
- Support the development and use of alternative addiction treatments such as buprenorphine. Support the use of office-based prescribed treatments including methadone and buprenorphine as appropriate for substance abuse treatment. Support research into other promising addiction treatments.

Systemic Barriers to Care

The following section lists systemic issues that may affect the quality and availability of care. These issues are listed alphabetically, in non-prioritized order. Not all of the issues below affect care to the same degree, and not all apply to every region of California.

Culturally Responsive Services

In a region as culturally diverse as California, it is vital that providers offer services that respond to the specific cultural needs and backgrounds of their service populations. A lack of service providers who reflect or understand the ethnic, cultural, or lifestyle background of the individuals they serve, or who do not have staff available who speak a client's language, can result in miscommunication, misunderstanding, or a lack of trust between provider and patient. The lack of culturally responsive services can contribute to the hesitance on the part of some PLWH to seek services or support. In California, ensuring linguistic competence increasingly means not only providing services in English and Spanish, but also translation for the hearing impaired and for individuals who speak other languages, including the more than 100 Asian dialects and languages spoken in California.

This category encompasses significant gaps and disparities facing the HIV care system. In some parts of the state, services tailored to the needs of specific groups such as communities of color, women, transgender people, and young people are not available. There is sometimes an absence or shortage of service staff who relate to and understand the particular lifestyles, needs, or cultural backgrounds of their HIV-infected patients. Lack of culturally appropriate care can increase patients' reluctance to visit providers or to disclose personal information and can lead to inappropriate or substandard service and support. It is, therefore, important that HIV providers strive to understand and respond appropriately to the varying needs of diverse populations.

- ❖ Ensure culturally appropriate services are available for all PLWH. Support effective training in cultural competency for all CARE Act-funded programs and providers. Continue supporting community-based services and programs targeting specific communities or populations. Ensure translation services are available for all PLWH who need them.

Data Collection, Evaluation, and Outcomes Tracking

Many believe problems with data reporting and a lack of effective evaluation of care services and client outcomes are serious issues for care providers. These issues can prevent care providers from identifying successes, disseminating successful models, accurately demonstrating need, and being fully accountable to funders. Coordinated data collection, program evaluation, and targeted research can help identify emerging issues, identify service gaps and disparities, maintain quality care, and improve client outcomes.

Data collection, in particular, has become a barrier to effective evaluation and program accountability. This task is especially cumbersome for agencies with multiple funding sources. HIV service providers are often forced to collect and report data into multiple reporting systems because each of their programs has different reporting requirements and a different reporting system. Duplicative reporting requires significant staff time and is especially difficult in times of shrinking budgets and increasing demand for services.

Agencies could benefit more from the data collected and reported if they had the resources and the training to produce reports, analyze data and evaluate services effectively. For example, many required reporting systems do not have simple mechanisms for querying the database and generating custom reports. Additionally, program reporting systems are often not linked together at the provider level, making it particularly difficult for an agency to get a complete picture of the services a client receives.

In addition to better program evaluation and accountability, with the appropriate reporting systems in place, service providers can better manage the quality of their care, maintaining, improving, or revising services in response to client needs and to changes in the standards of HIV care. Increasingly, an agency must be able to effectively evaluate their program services and to ensure quality management activities in order to secure and retain funding.

- ❖ Provide agencies with the resources, training, and technical assistance needed to collect, enter, report, and analyze program data. Support coordination of multiple reporting requirements and the federal, state, and local levels to reduce the administrative burden on providers.

Integration of Care

The quality, scope, and coordination of care for PLWH in California is affected by the ability of providers to plan and develop collaborative, multidisciplinary approaches to HIV service and care, especially in light of the changing, complex needs of those affected by the epidemic. Opportunities and incentives must be developed for increased interaction and service integration among consumers and all providers of HIV care and treatment, to include CARE Act grantees, HIV/AIDS and non-HIV/AIDS-specific agencies, local health jurisdictions, medical and psychosocial providers, public and private funders, governmental bodies, local and national agencies, and HIV planning groups. Infrastructure support should be provided for coordination. Planners, funders, and policy makers should support agency mergers and collaborations.

- Support the development of integrated, interdisciplinary models of care to ensure greater coordination among the primary care provider, specialty providers, case managers and psychosocial services professionals. Support agency mergers and collaborations when possible.
- Encourage integration of local planning and collaboration among all CARE Act grantees and other public and private funders in order to ensure maximization of available resources and development of a comprehensive continuum of care within each region.

Quality Management

The effectiveness or appropriateness of HIV services can sometimes be compromised where there are no quality measures to assess whether or not services are being provided according to established standards of care, or if they are being provided in a manner that is appropriate to each individual's condition. Disparities in service can also occur if there are no systems to ensure comparable service quality or availability across regional systems of care.

- Encourage the data collection and analysis needed for quality management, including support for electronic medical records, and systems to minimize medical errors. Fund information technology to improve the quality of services for PLWH and incorporate it into best practices.

Staff Turnover and Burnout

Many HIV service organizations have problems in retaining staff members over long periods of time and in rapidly filling key positions. Staff turnover disrupts trusting relationships developed over time between clients and staff members and creates ongoing training needs. Factors contributing to this problem can include low pay, long hours, the emotionally draining nature of the work, job instability caused by a lack of multiyear funding commitments, and competition in certain professional fields such as nursing and social work.

- Support professional development and training for HIV providers. Increase funding levels to help agencies retain qualified, experienced staff. Encourage agencies to develop policies and programs to counter staff burnout and reduce turnover.

Transgender Service Issues

Continued discrimination and violence against transgender individuals puts them at increased risk for HIV and makes it difficult for them to access many services. In San Francisco alone, 35 percent of all male-to-female transgender women are estimated to be living with HIV, yet access to comprehensive services throughout the state remains an issue. State laws protecting transgender individuals from discrimination were passed in 2005 and went into effect on January 1, 2006. Recent studies in Los Angeles and San Francisco have shown extremely high seroprevalence rates and risk behaviors in the transgender community, and have also shown that discrimination is a barrier to care. Transgender individuals face difficulty finding jobs, housing, and other basic services, and many turn to sex work as an alternative. In addition, many providers are unfamiliar with or uncomfortable serving transgender consumers, creating significant gaps in the system of care.

Assembly Bill (AB) 1400, authored by Santa Cruz Assemblyman John Laird, amended California's public accommodation law to make clear that transgender people are protected. AB 1586, authored by Assemblyman Paul Koretz, prohibits discrimination against transgender people by the insurance industry, including health care insurers.

- Equality California.

Federal use of the categories of "male" and "female" in collecting HIV/AIDS case data forces epidemiologists to under-report or mis-report the rate of HIV infection among transgender individuals in federal reports, and creates a barrier to full and accurate reporting on the true nature of the HIV/AIDS epidemic among transgender persons. Consistent categories are needed on a nationwide basis to allow for full and accurate reporting of HIV incidence across the full range of gender categories.

Goals

- Address the needs of transgender PLWH in the design of service programs, including but not limited to outreach, primary care, substance abuse, gender transition therapies, mental health, and housing services.
- Provide training and support for providers to offer culturally appropriate services to transgender PLWH.
- Actively include representation of transgender individuals in epidemiological and data collection activities as well as community planning. Use appropriate gender categories for data collection and research.
- Conduct more research on the service needs and barriers to care for transgender PLWH.

Translation and Interpretation Services

Language and cultural barriers create significant problems for PLWH whose primary language is not English, particularly in terms of the lack of professional and paraprofessional providers who are bilingual in either English and Spanish or in English and one or more Asian/Pacific Islander languages. In addition to the huge number of people in California who speak Spanish as their primary language, more than 100 different Asian/Pacific Islander languages and dialects exist in our state. Deaf individuals living with HIV also need American Sign Language interpretation and access to interpretation technology. Translation and interpretation services provide an essential means for medical and other providers to communicate with non-English-speaking clients, resulting in the sharing of information that can enhance the quality and length of the patient's life.

Translation and interpretation services, however, must always be culturally specific, delivered by individuals who understand not only the patient's language or dialect, but also his or her specific cultural perspectives and backgrounds. These cultural differences can often impair a clear understanding of a specific question a patient may be asking, or of a specific need for services, despite the apparent ability to track what is being spoken in a literal sense.

- Encourage agencies to hire a multi-lingual, multi-cultural staff at every level of care to avoid the need for separate translation services whenever possible.
- Provide translation and interpretation services for providers who do not speak the client's primary language to communicate medical and support information. Ensure that translation and interpretation services are culturally specific. Reduce dependence on children or other family members for translation. Provide interpretation and translation to enable deaf and monolingual PLWH to participate in community planning efforts.

Transportation Services

Lack of consistent access to transportation remains a barrier to accessing HIV services for some people. This problem exists in both rural and urban settings. In rural areas, those without public transit, and areas with widely dispersed services, transportation is a service gap that leads directly to other service gaps for PLWH. Finding practical solutions to the problem would contribute toward ending HIV service disparities across the state, while improving access to health and social services for clients. As with child care and other services, the inability to access this supportive service creates a systemic barrier to accessing medical and social services.

Ensuring full access to comprehensive transportation services remains a central need for PLWH. Transportation is often the only means to ensure accessibly of medical and social services for PLWH, and to support full adherence to treatment regimens. Yet, many areas lack adequate public transportation resources or subsidies, and increasing gasoline prices greatly affect the cost of commercial transportation services.

Enhancement of transportation services must include both access to a full range of transportation options, and subsidization of transportation costs, including transportation suitable and accessible to persons with disabilities other than HIV.

Transportation issues are of particular importance in areas in which PLWH must travel long distances to access care. In such regions, van-based services are often the only alternative to daylong bus rides or expensive taxi fares. Yet, van services are also expensive to provide and can serve only a limited number of consumers per day, particularly when they must travel a long distance to pick up and drop off each consumer.

Transportation is a critical component of the overall continuum of care whose costs continue to accelerate on an ongoing basis. As the HIV/AIDS service system strives to create expanded and enhanced services to meet the demand for comprehensive systems of care, the demand for expanded transportation services also increases, placing greater cost demands on the system as a whole. These service repercussions must be taken into account both when planning for and mandating new services within jurisdictions or regions.

- ❖ Ensure full access to comprehensive transportation services for PLWH, including access to a full range of transportation options, and subsidization of transportation costs, including transportation suitable and accessible to persons with disabilities other than HIV.

Women

Women are a comparatively small part of the HIV/AIDS epidemic in California; however, that proportion continues to grow, and women of color bear a disproportionate share of the epidemic among women. As described in the Los Angeles *CARE Act Year 15 Title I Application*, "Women with HIV of all racial and ethnic groups are particularly vulnerable to a variety of barriers which prevent them from accessing care: lack of child care, serving as single heads of households, transportation challenges, and medical care which does not always address the specific needs of female patients."[21]

Perhaps because of their smaller numbers, a comprehensive continuum of care is less readily and regularly available for women than for men. A comprehensive continuum of women's HIV services must include women-focused and women-friendly primary and specialty medical care, especially in obstetrics and gynecology; family planning and prenatal care; mental health services; women-only support groups; child care; transportation; housing; food; and access to public benefits programs. Ideally, this includes the availability of women medical and psychosocial providers from a variety of ethnic and linguistic backgrounds. Women living with HIV have reported their frustration with doctors who did not recognize potential HIV symptoms in women, including frequent vaginal infections, or who did not recognize differences in potential medication

[21] Los Angeles EMA Title I Application, 2005, p. 43.

therapies and prescriptions for women as opposed to men. Finding pre-conception counseling or an obstetrician with expertise in preventing perinatal transmission can be very difficult, especially outside of major urban areas.

Many providers noted that because women have such specific and distinct needs in regard to HIV/AIDS support and treatment services, the existing male-centered system often unwittingly creates insurmountable barriers to women accessing adequate HIV/AIDS care. In many cases, this will require reorganizing existing systems of care to respond to both women and men, or, in other cases, creating entirely new systems of care that recognize the distinct service requirements of women and that build service systems and networks consistent with their needs. While many women with HIV have dependent children, many women with HIV do not have children, or do not have custody of their children, and may not feel comfortable accessing care in clinics organized around family services.

Women tend to enter the care system later in the disease process than men, and they often experience severe social isolation; have problems with transportation; and find it a challenge to regularly attend support groups. The stigma that still exists regarding HIV/AIDS among women is a further barrier to seeking early intervention and care. Women also risk receiving inadequate care when their individual needs are not completely or sensitively addressed, or when providers do not acknowledge or take into consideration their various family responsibilities, and how this may affect their ability to access services or follow-through on referrals.

Goals

- Address the special needs and concerns of HIV-infected women including access to women-focused primary care, regular gynecological care, support groups, housing, transportation, and mental health counseling. Ensure providers are trained in the medical needs of women with HIV, including gynecological symptoms and opportunistic infections, or potential hormone interactions with HIV medications. Provide pre-conception counseling and comprehensive prenatal care to women and their partners considering pregnancy.
- Address domestic violence and stigma as barriers to care for women, and the isolation experienced by many women with HIV/AIDS. Provide peer-based programs to educate women about their health and promote self-empowerment programs for HIV-positive women.
- Support the development of systems of care designed to address women's needs, including those of women with dependent children. Support increased participation by women in clinical trials.
- Ensure that all California pregnant women have early access to HIV diagnosis and treatment, including ARV therapy, along with strong protections of personal confidentiality and choice. Ensure implementation of prenatal guidelines through clinician education and training. Facilitate access to HIV specialists with expertise in preventing perinatal transmission.

- ❖ Continue to reduce the rate of perinatal HIV transmission to zero. Ensure continued comprehensive HIV education for clinicians to allow them to provide HIV education, testing, and interventions designed to reduce perinatal HIV transmission. Encourage labor and delivery sites to offer rapid testing to women who have not tested or sought prenatal care, referral to appropriate specialists, and obstetrical interventions designed to reduce mother to child transmission. Support policy development in hospitals to appropriately incorporate rapid testing into labor and delivery settings as part of the standard of care. Ensure that confidentiality is a high priority in perinatal settings.

Young People and Adolescents

Providing care to HIV-positive youth poses a special challenge. Frequently, young people have difficulty accessing services designed for adults. Substance abuse, homelessness, poor support systems, and histories of trauma and mental illness complicate service delivery. Because they often do not have family in the area and have few options for supporting themselves, many youth need specialized housing. Queer youth may experience rejection by the medical establishment. Youth who are homeless or marginally housed are often distrustful of traditional "adult" services. Services need to be designed to keep young people actively engaged in their own care.

Pediatric providers are now seeing perinatally infected children aging into adolescence, which presents new, though welcome, challenges. The Los Angeles Family AIDS Network, a Title IV group, says, "the pediatric population is aging into the adolescent years and pediatric providers are working to offer youth sensitive services that meet the maturation needs of these youth. Pediatric providers increasingly collaborate with traditional youth providers as warranted by the individual client's circumstance. Of particular interest is that a focus of many of these patients is now looking ahead to issues related to college and employment."[22]

Goals

- ❖ Ensure that as more young people (18-24) and adolescents (13-17) are affected by HIV/AIDS, specialized service continuums are developed and refined for all youth, including non-traditional testing and outreach programs, accessible and specialized medical care services and clinic times that are tailored to young people. Design services to reach high-risk youth, including gay or transgender young people and homeless youth.
- ❖ Provide increased substance abuse services for young adults living with HIV; increased access to specialized mental health treatment services; increased availability of housing, transportation, and social support services; and increased support for young adults transitioning out of incarceration settings.

[22] Los Angeles Family AIDS Network (LAFAN) Ryan White Title IV Coordinated Services and Access to Research For Women, Infants, Children, and Youth FY 2005. p. 5.

- Increase efforts to encourage and facilitate expanded, voluntary HIV testing by young people. Provide specialized prevention interventions for young PLWH that utilize approaches and systems distinct from those focused on HIV-positive adults.
- Provide accurate, comprehensive pre-adolescent and adolescent sex education to prevent and mitigate the transmission of HIV and other STDs among young people.

APPENDICES

Appendix A: CHPG Members

Appendix B: California CARE Act Grantees

Appendix C: SCSN Review Meeting Participants

Appendix A: CHPG Members

Fritzic Allen, Jr.,
Early Intervention Program
County of Fresno
Fresno, CA

Rachel Anderson
University of California, Davis
Davis, CA

Bart Aoki
Universitywide AIDS Research Program
Oakland, CA

William Blum
San Mateo County AIDS Program
San Mateo, CA

Sylvia Britt-Raven
W.O.R.L.D.
Oakland, CA

Cesar Cadabes
Pasadena, CA

Michael Cunningham
Deputy Director
Prevention Services Division
California Department of Alcohol
and Drug Programs
Sacramento, CA

John Elfers
Office of Education
San Luis Obispo County
San Luis Obispo, CA

Kevin Farrell, L.C.S.W., Chief
HIV Education and Prevention
Services Branch
Office of AIDS
California Department of Health Services
Sacramento, CA

Carolina Gonzalez-Garcia
San Ysidro Health Center
San Ysidro, CA

Arturo Hernandez
Palm Desert, CA

Kevin Hutchcroft
HIV/AIDS Prevention and Control Program
Public Health Department
Santa Clara County
San Jose, CA

Anthony Iton, M.D., J.D., M.P.H.
Alameda County
Oakland, CA

Sabina Laveaga
Imperial County Public Health Department
El Centro, CA

Greg Mehlhaff
STD/HIV Prevention Training Center
California Department of Health Services
Oakland, CA

Vicki Mizel
Assistant Deputy Director
Health Policy and Regional
Support Program
San Diego, CA

Tracey Packer
Interim Director of HIV Prevention
San Francisco Department of Public Health
San Francisco, CA

Mario Perez
Office of AIDS Programs and Policy
Department of Health Services
Los Angeles County
Los Angeles, CA

Ricki Rosales
AIDS Coordinator's Office
City of Los Angeles
Los Angeles, CA

Bamby Salcedo
Sherman Oaks, CA

Jamila Shipp
Oakland, CA

Clarence Smelcer
Native American Health Center
San Francisco, CA

Sharla Smith
HIV/STD Prevention Education
School Health Connections
Healthy Start Office
California Department of Education
Sacramento, CA

Frank Strona
STD Prevention and Control Services
San Francisco Department of Public Health
San Francisco, CA

Ellen Swedberg
Department of Health Services
County of Sonoma
Santa Rosa, CA

Peg Taylor, Chief
HIV Care Branch
Office of AIDS
California Department of Health Services
Sacramento, CA

Laura Thomas, M.P.H., M.P.P.
Continuum
San Francisco, CA

Jason Tokumoto, M.D.
Assistant Clinical Professor of Medicine
HIV Telephone Consultation Service
University of California, San Francisco
San Francisco, CA

Barbara Weiss
HIV/AIDS Coordinator
Program and Fiscal Policy Branch
California Department of Alcohol and Drug Programs
Sacramento, CA

Freddie Williams
Palmdale, CA

Appendix B: California CARE Act Grantees

Ronald Person, Director
Office of AIDS
Alameda County Health Services
Oakland, CA

Mario Perez
Acting Director
Commission on HIV Health Services
Office of AIDS Programs and Policy
Department of Health Services
County of Los Angeles
Los Angeles, CA

Donna Flemming
Program Manager
Orange County Health Care Agency
Santa Ana, CA

Adrienne Rogers
Health Program Coordinator
AIDS Service Programs
Health and Human Services
Sacramento County
Sacramento, CA

Gary McBride
Chief of Administrative Services
Department of Public Health
San Bernardino County
San Bernardino, CA

Terry Cunningham, Chief
San Diego HIV CARE Coalition
Office of AIDS Coordination
County of San Diego
San Diego, CA

Michelle Dixon Long, Director
HIV Health Services AIDS Office
Department of Public Health
San Francisco, CA

Shari Brenner
AIDS Section Manager
AIDS Unit
Department of Health Services
County of Sonoma
Santa Rosa, CA

Kevin Hutchcroft
Program Director
HIV/AIDS Prevention and Control Program
San Jose, CA

Victoria Derrick
East Valley Community Health Center, Inc.
West Covina, CA

Karen Peterson
High Desert Hospital
Lancaster, CA

Catherine Rada
Mendocino Community Health Clinics
Ukiah, CA

Alexander Taylor
Public Health Department
San Bernardino County
San Bernardino, CA

Lois Lindsey
Tri-City Health Center
Fremont, CA

Diana Goulet
Ventura County Health Care Agency
Ventura, CA

Daryl Leong, M.D., M.P.H.
Alta Med Health Services Corporation
Los Angeles, CA

Andrew Signey
Catholic Healthcare West
Long Beach, CA

Marty Keale
Center for AIDS Research, Education, and Services
Sacramento, CA

Rosanna Scolari
Centro De Salud De La Comunidad San Ysidro
San Ysidro, CA

Chris Hall
Community Hospital of the Monterey Peninsula
Monterey, CA

Cecilia Casillas
Community Medical Center
Stockton, CA

Steve Havenner
Los Angeles Gay and Lesbian Center
Los Angeles, CA

Anne McAfee, R.N.
Mendocino Community Health Clinic, Inc.
Ukiah, CA

Jennifer Salerno
Natividad Medical Center
Salinas, CA

Alicia Liriano
North County Health Project
San Marcos, CA

Jose Paredes
Northeast Valley Health Corporation
Panorama City, CA

Jay Molofsky
Open Door Community Health Centers
Eureka Community Health Center
Eureka, CA

Allen Meyer, J.D.
San Francisco Community Clinic Consortium
San Francisco, CA

Dan Reid
Santa Barbara County Health Department
Santa Barbara, CA

Dena Dickinson
Department of Public Health
Santa Clara County
San Jose, CA

Venice Family Clinic
Venice, CA

Diane Goulet, R.N.
Ventura County Health Care Agency
Ventura, CA

Yvette Wells, R.N.
Watts Healthcare Corporation
Los Angeles, CA

Kim Lawton
West County Health Centers, Inc.
Guerneville, CA

Alvan Quamina
Sexual Minority Alliance of Alameda County
Oakland, CA

Susan Lawrence
The Catalyst Foundation
Lancaster, CA

Manfred Hayes
HIV ACCESS
Tri-City Health Center
Freemont, CA

Mary Dugom
Community Hospital of the
Monterey Peninsula
Monterey, CA

Jennifer Salerno
Natividad Medical Center
Salinas, CA

Karla Burnworth
Plumas County Public Health Agency
Quincy, CA

Jonathan Mesinger
Department of Hospitals and Clinics
San Mateo County
San Mateo, CA

David Burden
Charles R Drew University of
Medicine and Science
Los Angeles, CA

Linda Low or Juan Garcia
Clinica Sierra Vista
Bakersfield, CA

Christine Leiverman
Contra Costa County Health
Services Department
Martinez, CA

Irene Tyrrell
County of Orange
Santa Ana, CA

Katherine Rubin
Del Norte Clinics, Inc.
Chico, CA

Carlos Peralta, M.D.
El Proyecto Del Barrio
Arleta, CA

Iris Payne
Family Health Centers of San Diego, Inc.
San Diego, CA

Robyn Gonzales
Fresno Community Hospital and
Medical Center
Dba University Medical Center
Fresno, CA

Karla Burnworth
Plumas County Public Health Agency
Quincy, CA

Kathy Glasgow
Regents of University of California
San Diego, CA

Eric Frykman
San Bernardino County Public
Health Department
San Bernardino, CA

Laurie Hauer, R.N., M.P.A.
Santa Cruz County
Santa Cruz, CA

Crystal Garnder, R.N.
Shasta Community Health Center
Redding, CA

Peter Turner
Solano County Health and Social
Services Department
Vallejo, CA

Debra George-Barber, M.D.
T.H.E. Clinic, Inc.
Los Angeles, CA

Tom Martinez, M.S.W.
Tarzana Treatment Centers, Inc.
Tarzana, CA

Tracy Brown
Tenderloin AIDS Resource Center
San Francisco, CA

Susan Lawrence, MD
The Catalyst Foundation. for
AIDS Awareness and Care
Lancaster, CA

Mark Matlock
School of Medicine
University of Southern California
Los Angeles, CA

Debbie Titmus
Sonoma County Health
Services Department
Santa Rosa, CA

Jennifer Zogg
University of Southern California
Los Angeles, CA

Hazel Wesson
AIDS Project East Bay
Oakland, CA

Michael Green
Department of Health Services
County of Los Angeles
Los Angeles, CA

William Cunningham, M.D.
Schools of Medicine and Public Health
University of California, Los Angeles
Los Angeles, CA

Steve Morin, Ph.D.
Prevention for Positives Center
University of California, San Francisco
San Francisco, CA

Urban Indian Health Board
Oakland, CA

Marcy Kaplan
Public Health Foundation Enterprises, Inc.
Los Angeles, CA

Mary Caffery, R.N., M.S.N.
Regents of the University of California
San Diego, CA

Daniel Barba
Children's Hospital Medical
Center of Northern California
Oakland, CA

Sherilyn Adams
Executive Director
Larkin Street Youth Services
San Francisco, CA

Connie Young, R.N.
Fresno Community Hospital
and Medical Center
Fresno, CA

Esperanza Pallana
San Francisco General Hospital
University of California, San Francisco
San Francisco, CA

D. Sylves
Organization to Achieve Solutions in
Substance-Abuse, Inc. (OASIS)
Oakland, CA

William Christopher Mathews
Regents of University of California
San Diego, CA

Leticia Cazares
San Ysidro Health Center
San Ysidro, CA

Neil Flynn, M.D., M.P.H.
AIDS ETC
University of California, Davis
Sacramento, CA

Chris Mathews, M.D.
AIDS ETC
University of California, San Diego
San Diego, CA

Ronald Goldschmidt, M.D.
Department of Family and Community Medicine
San Francisco General Hospital
University of California, San Francisco AETC
San Francisco, CA

John Beleutz, M.P.H.
Health Education and Training Center
Division of Community Health Partnership
San Jose AETC
San Jose, CA

Marshall Kubota, M.D.
North Coast Area AIDS ETC
Academic Foundation for Excellence in Medicine
Sonoma County
Santa Rosa, CA

Michael Reyes, M.D., M.P.H.
Pacific AETC
Department of Family and Community Medicine
University of California, San Francisco
San Francisco, CA

Mary Wallace, M.A., F.A.C.H.E.
San Joaquin Valley AETC
San Joaquin Valley Health Consortium
Fresno, CA

Peter Katsufrakis, M.D., M.B.A.
Keck School of Medicine
University of Southern California AETC
Los Angeles, CA

Tom Donohoe, M.B.A.
Department of Family Medicine
University of California, Los Angeles AETC
Los Angeles, CA

Allen Funnyé, M.D., F.A.C.P.
Drew University AETC
Charles R. Drew University of Medicine and Science
Los Angeles, CA

Kathleen Clanon, M.D., F.A.C.P.
East Bay AIDS ETC
HIV Services (QIC 22138)
Alameda County Medical Center
Oakland, CA

Jeremiah Tilles, M.D.
AIDS ETC
University of California, Irvine
Orange, CA

Richard Fredekind
School of Dentistry
University of the Pacific
San Francisco, CA

Roseann Mulligan
School of Dentistry
University of Southern California
Los Angeles, CA

William Bird
School of Dentistry
University of California, San Francisco
San Francisco, CA

Leticia Torres
Department of Dental and Oral Surgery
Highland Hospital/Alameda County Medical Center
Oakland, CA

No-Hee Park
School of Dentistry
University of California, Los Angeles
Los Angeles, CA

Thomas Rogers
School of Dentistry
Loma Linda University
Loma Linda, CA

Appendix C: SCSN Review Meeting Participants

Daniel Perez
Inland Empire EMA
Colton, CA

Joe Acosta, Chair
Inland Empire HIV Planning Council
Palm Springs, CA

Victoria Jauregui Burns
HIV/AIDS Program Chief
Riverside County
Riverside, CA

Mario Perez
Office of AIDS Programs and Policy
Department of Health Services
County of Los Angeles
Los Angeles, CA

Craig Vincent-Jones
Executive Director
Commission on HIV
Los Angeles, CA

Maria Aguilar
Office of AIDS Administration
Oakland EMA
Oakland, CA

Terry Cunningham, Chief
HIV, STD, and Hepatitis Branch
Public Health Services
Health and Human Services Agency
San Diego, CA

Elizabeth Brosnan
Vice-Chair- San Diego Planning Council
Executive Director - Christie's Place
San Diego, CA

Michelle Long, Director
HIV Health Services
AIDS Office
San Francisco Department of Public Health
San Francisco, CA

Randy Allgaier, Co-Chair
San Francisco EMA Planning Council
San Francisco, CA

Sparkie Spaeth
Community Health and Prevention Manager
Department of Health and Human Services
Marin County
San Rafael, CA

Ellen Sweetin, Director
AIDS Program
San Mateo County Public Health
San Mateo, CA

Kevin Hutchcroft, Director
HIV/AIDS Prevention and Control Program
Santa Clara County Health and Hospital Systems
San Jose, CA

Jerry Larson, Chair
Health Connections
San Jose Planning Council
San Jose, CA

Peter Katsufrakis, M.D., M.B.A.
Associate Dean
Keck School of Medicine
University of Southern California
Los Angeles, CA

Kim Lawton
HIV Program Coordinator
West County Health Centers
Guerneville, CA

Andrew Signey, Director
CARE Program and Clinics
CARE Program
CHW – St. Mary Medical Center
Long Beach, CA

Barbara Weiss
HIV Coordinator
Program and Fiscal Policy Branch
California Department of Alcohol and
Drug Programs
Sacramento, CA

Duduzile Zondo-Goins, Director
Larkin Street Youth Services
Health Services
San Francisco, CA

Jeff Byers
EMA Liaison
Office of AIDS
California Department of Health Services
Sacramento, CA

Jim Taylor
Highland Hospital
Oakland, CA

Lori Williams
Oakland EMA
Oakland, CA

Christine Leivermann, Director
AIDS Programs
Department of Health Services
Contra Costa County
Martinez, CA

Donna Fleming
HIV Planning and Coordination
Orange County Health Care Agency
Santa Ana, CA

Martin Salas, M.S.
Co-Chair
Orange County Planning Council
Irvine, CA

Adrienne Rogers
Department of Health and Human Services
Sacramento County
Sacramento, CA

Joseph Robinson, Chair
Sacramento Planning Council
Sacramento, CA

Shari Brenner
HIV/AIDS Section Manager
Center for HIV Prevention and Care
Santa Rosa, CA

Allen Nishikawa
Sonoma EMA Planning Council
Public Health Division
County of Sonoma
Santa Rosa, CA

Rick Dean
Executive Director
Face to Face
Sonoma County AIDS Network
Santa Rosa, CA

John Mortimer, Ph.D., Consultant
Northern California Grantmakers
San Francisco, CA

Xushie Brue
Dental Reimbursement
Alameda County Medical Center
Oakland, CA

Leticia Cazares
HIV Operations Manager
San Ysidro Health Center
San Ysidro, CA

Marcy Kaplan, Director
Los Angeles Family AIDS Network
Los Angeles, CA

Michael Montgomery, Chief
Office of AIDS
California Department of Health Services
Sacramento, CA

Barbara Bailey
Assistant Chief
Office of AIDS
California Department of Health Services
Sacramento, CA

Peg Taylor, Chief
HIV Care Branch
Office of AIDS
California Department of Health Services
Sacramento, CA

Kathleen Russell, Chief
AIDS Drug Assistance Program Section
Office of AIDS
California Department of Health Services
Sacramento, CA

Carol Russell, Chief
Early Intervention Section
Office of AIDS
California Department of Health Services
Sacramento, CA

Jim Zuber, Chief
Community Based Care Section
Office of AIDS
California Department of Health Services
Sacramento, CA

Therese Ploof, Chief
AIDS Drug Assistance Program Unit
Office of AIDS
California Department of Health Services
Sacramento, CA

Carol Crump
Early Intervention Section
Office of AIDS
California Department of Health Services
Sacramento, CA

Laura Thomas, Consultant
SCSN Writer
San Francisco, CA

Susan Strong
Consultant/Facilitator
Strong Consulting
Vallejo, CA